"METHODOLOGIES TO IDENTIFY WORK-RELATED DISEASES – REVIEW OF SENTINEL AND ALERT APPROACHES"
BRUSSELS, 18TH MAY 2017

The objective of the workshop was to share experience on existing alert and sentinel systems, as well as other monitoring systems presenting features also suitable for the early detection of emerging work-related diseases (WRDs), and to gain more insight on the drivers and obstacles to the implementation of alert and sentinel systems. A further aim of the workshop was to formulate recommendations for the development and use of such systems improving the early detection of work related diseases and the timely set up of evidence-based prevention. It brought together around 30 experts with different backgrounds (owners and developers of monitoring systems, researchers, actors from occupational disease recognition and compensation) and provided a platform for discussion on different aspects of these systems.

The workshop built on a review of a number of existing alert and sentinel approaches (see report "Methodologies to identify work-related diseases: Review of sentinel and alert approaches") that EU-OSHA commissioned to a research team made of KU Leuven, the Coronel Institute, the Finnish Institute of Occupational Health, the University of Manchester and the University of Bologna.

The workshop was kicked-off by **Elke Schneider** from EU-OSHA who welcomed participants and introduced the workshop agenda. This one-day event included plenary sessions in the morning while the afternoon session was dedicated to an interactive exercise with active discussions in four small groups using World Café methodology. The workshop was closed with a summary of the most important discussion points and final conclusions.

An overview of the project was given by the EU-OSHA project manager **Emmanuelle Brun**. explaining the importance and challenges of the identification of new and emerging risks and the prevention of work-related diseases, which are key strategic objectives of the EU Strategic Framework on Health and Safety at Work 2014-2020 and priorities in EU-OSHA's Multi-annual Strategic Programme 2014-2020.

Under its Multi-annual Strategic Programme 2014-2020, EU-OSHA has been carrying out several projects on work-related diseases (WRDs). Three of these projects were commissioned the above mentioned research team together with TNO Netherlands.

- "Rehabilitation and return-to-work after cancer – Instrument and practices",
- "Review of specific work-related diseases due to biological agents", and
- "Methodologies to identify work-related diseases – review of sentinel and alert approaches" which was the focus of the workshop.

Presentation of the project "Methodologies to identify work-related diseases – Review of sentinel and alert approaches"

The morning session of the workshop started with the presentation of the project and first results. Firstly, **Lode Godderis** from the Centre for Environment and Health of the University

of Leuven began by giving an overview of the project and the method applied. The project consists of five main tasks:

- Task 1. Desk research — literature review.
- Task 2. In-depth description of a selection of 12 sentinel or alert approaches from Task 1
- Task 3. Support for the organisation of the present workshop to discuss the outcome of Tasks 1 and 2.
- Task 4. Production of a final report including analysis and policy options.
- Task 5. Support for a workshop to disseminate findings to stakeholders.

Lode Godderis then presented the results of Task 1 literature review which has generated an overview and typology of existing alert and sentinel systems and monitoring systems that can be used to identify emerging WRDs.

Task 2 in-depth description was presented by **Annet Lenderink** from the Coronel Institute of the University of Amsterdam. Annet Lenderink explained that six systems out of twelve analysed in this task were described through in-depth desk-research and the other six systems were additionally described through interviews with stakeholders. Annet Lenderink briefly presented the main characteristics of the examined alert and sentinel systems with some illustrative examples of their results.

Discussions

Characteristics of alert and sentinel systems

The presentations of the results obtained in the first project steps were followed by some interesting questions and discussion. Participants asked for clarification about the criteria used by the various systems for the determination of work-relatedness. Lode Godderis explained that the approach and main evaluation steps were similar in most of the sentinel and alert approaches analysed in this study, but some criteria vary. There was an agreement among the participants that, in this type of systems and approaches, it is the *likelihood* rather than the *certainty* of causal relation with work that the experts involved in the evaluation of the work-relatedness determine. However, this does not have to be seen as a weakness of the systems because the main objective of sentinel and alert systems is detection of work-related diseases and their prevention, rather than compensation of occupational diseases. With less strict criteria for work-relatedness, the likelihood to detect and prevent a WRD is greater. Indeed, proving a 100% causality from work in the case of a work-related disease is often impossible. It was concluded that, in fact, for alert and sentinel systems it is more important to capture as many events and signals as possible to better detect and prevent WRDs, in particular new/emerging risks and diseases, rather than having a strict and commonly agreed definition of WRDs.

The discussion also focused on the need for clearer information on systems that allow capturing new WRDs versus monitoring systems in occupational health in general. Annet Lenderink explained that it is not always so that the information available about the systems clearly mentions whether the system captures new WRDs. It is often necessary to look into the systems in depth in order to understand their capacity to detect new diseases. The literature review carried in the scope of this project provides an overview of the existing monitoring systems and sentinel and alert approaches that the research team

considered most suitable to capture new/emerging WRDs based on an analysis of the system's design and characteristics.

- **Approaches not included in the literature review**

The discussions that took place at the workshop (as well as during the workshop preparation with experts who could not attend the workshop) allowed to learn about additional approaches that were not captured in the literature review. These systems were not identified in the literature review either because they were not described in the published scientific literature at the time the research team carried out the literature review, or because they did not fit in according to the inclusion/exclusion criteria defined in the search strategy.

For example, the experts from the French national public health agency (Santé publique France) mentioned that in 2010 their agency implemented cohorts for epidemiological surveillance of workers *(Cohortes pour la surveillance épidémiologique en lien avec le travail, Coset)* with the purpose to better describe and monitor the links between occupational factors and the occurrence of health problems (muscular and joint problems, mental health problems, cardiovascular and respiratory problems, cancer, etc.). This program aims to identify occupations and working conditions at risk, quantify occupational factors causing adverse health effects and propose recommendations for prevention. Both exposure and health effects are assessed with questionnaires given to the participating groups of workers (agricultural workers, workers in general, etc.), with the possibility to complement these data with the national health insurance database.

Experts from the German Bundesanstalt für Arbeitsschutz und Arbeitsmedizin (BAuA) consulted on the literature review report had also provided information on existing approaches useful to tackle WRDs, including new risks, in Germany:

- In Germany, statistics about health in different jobs and branches are included in the annual statistics of health insurance companies (Allgemeine Ortskrankenkasse AOK, Betriebskrankenkasse BKK-Bundesverband, DAKGesundheit, etc.). BAuA (Bundesanstalt für Arbeitsschutz und Arbeitsmedizin) uses these data to analyse the occurrence of sick leave in single occupations. The data are regularly included in the BAuA's report on health at work (Sicherheit und Gesundheit bei der Arbeit, SuGA).
- The Robert Koch-Institut (RKI) regularly runs different large cross-sectional and follow-up studies to analyse health in the German population. These studies include occupational health aspects.
- BAuA regularly runs large cross-sectional studies (BIBB [Bundesinstitut für Berufsbildung]-BAuA-Survey, Arbeitszeitmonitoring) to monitor occupational exposures and related health outcomes (complaints). Among other ongoing studies, for example, the follow-up study "Studie zur Mentalen Gesundheit bei der Arbeit (S-MGA)" considers mental health and work.
- The German National Cohort (GNC), a joint interdisciplinary endeavour, is implemented by a national network of 25 German research institutions. Its overall aim is to investigate the causes underlying major chronic diseases such as cardiovascular diseases, cancer, diabetes, neurodegenerative/psychiatric diseases, respiratory and infectious diseases, and their pre-clinical stages or functional health impairments. Some occupational aspects are also considered in this study.

- Other ongoing epidemiological studies in Germany (for example, the Gutenberg-Health-Study) are used to analyse associations between occupational exposures (psychosocial aspects, shift work) and cardio-metabolic outcomes.

- As part of the annual statistics about notification, recognition and compensation of occupational diseases provided by the German Statutory Accident Insurance (DGUV), the so-called “Hautarzt-Verfahren” is an approach to detect, report and treat very early dermal work-related disease (eczema, skin cancers), whereas the so-called “Psychotherapeuten-Verfahren” is implemented to provide early psychotherapeutic measures after (occupational) accidents to avoid mental health problems. Yet other approaches are used for early (occupational) rehabilitation (for example, of musculoskeletal problems).

Last but not least, experts from the French EpiNano system explained that EpiNano will eventually consist on two approaches: non-compensation related surveillance based on self-assessment by exposed workers through a questionnaire; but also compensation-based, which has not started yet. This aspect was very interesting since the information found by the research team in the literature described EpiNano as an exclusively non-compensation related system.

Sharing experience on three sentinel systems: THOR (UK), RNVP3 (FR) and Sensor-Pesticides (USA)

Experts directly involved in their development and implementation presented the three systems and questions and discussions with the participants followed.

THOR system

By Raymond Agius, (Centre for Occupational and Environmental Health, University of Manchester), United Kingdom

Raymond Agius presented the different schemes existing as part of THOR (The Health and Occupation Research network), their scope, and challenges and gave concrete examples of new WRDs identified through the network. To the question from the audience as to why he only presented examples of work-related skin diseases identified by THOR, Raymond Agius explained that experts from THOR wish to raise awareness about work-related skin diseases, which are frequently reported to the system and seem to have an increasing incidence in certain groups of workers. He also explained that signals related to work-related skin diseases might be more easily picked up, compared to other diseases, in particular long-latency diseases such as cancers. However, establishing a causal link to exposure might be difficult. There are many issues with products not used for their original function and causing skin sensitisation (such as fragrances used in cleaning products). In addition, manufacturers of such products often change their formulation, which makes the determination of the cause-effect link difficult. Many products, such as fragrances, are not regulated under REACH and belong to low-regulated areas, which means that there is a lack of toxicological data about these. Hence the importance of alert systems in this area.

RNV3P System

By Vincent Bonneterre (Grenoble Teaching Hospital, Occupational and Environmental Diseases Centre) and Isabelle Vanrullen (Anses), France

Vincent Bonneterre and **Isabelle Vanrullen** presented the French system RNV3P (réseau national de vigilance et de prévention des pathologies professionnelles), the data mining methodology developed by their team, the newest features of the system and examples of new WRDs that the system allowed to identify. Comments from the audience were mainly related to the term "imputability" (i.e. intrinsic and extrinsic attributability), which required some clarification. Imputability literally means to attribute or ascribe. Vincent Bonneterre and Isabelle Vanrullen explained that this term is used in two contexts: where a physician describes imputability relying on the worker's "feeling" regarding work-relatedness; and where imputability is derived from an algorithm in relation to new/emerging WRDs.

Sensor-Pesticides system

By Walter Alarcon (National Institute for Occupational Safety and Health – NIOSH), USA

Walter Alarcon shared his knowledge and experience regarding the US system Sensor-Pesticides. Currently, NIOSH provides funding to eight States but the system is open to all States to report. Some States have the laws that require them to report cases but the main obstacle to participation in the system is a lack of financial resources.

Participants were particularly interested to know more about how case evaluation is done. Walter Alarcon explained that case evaluation is a process consisting of several steps. Sensor-Pesticides is based on a highly sensitive approach, whereby work-relatedness can be decided if at least two symptoms reported can be correlated to workplace factors. The first screening for case evaluation is done by an expert from the State Health Department, whereas the second level of quality control and evaluation is done by NIOSH. There is also a possibility to contact reporters in case of a need for clarification about the reported data.

Another question was related to the possibility to use the database for detection of long-term effects, such as occupational cancer. Walter Alarcon explained that SENSOR Pesticides is designed to detect the acute effects only of pesticides exposure. Nevertheless, there are other methodologies in place for the detection of long-term effects, for instance, a large cohort that focuses on the chronic effects among agriculture workers.

Finally, when asked about the use of paraquats in the US, Walter Alarcon explained that some substances that have been forbidden in Europe are still used in the US (such as paraquats). He also explained that NIOSH cannot directly forbid the use of a substance but can only provide scientific evidence against it. Other institutes, like the Environmental Protection Agency (EPA) can provide regulatory measures to restrict use of certain substances.

Interactive discussion: World café exercise

The afternoon session was dedicated to interactive discussion in the form of World café to address the following questions:

1. Drivers for alert and sentinel approaches/ monitoring systems suitable for detection of new work-related diseases (WRDs);

2. Obstacles of alert and sentinel approached/ monitoring systems for the identification of new WRDs;
3. The link with prevention; and
4. Alert function of systems.

Participants were divided into four groups around four tables and each group started the exercise with a different question. The groups then moved to another table to discuss the next question so that at the end of the session all groups had addressed all four questions. At each table, a "leader" remained at the same table throughout the entire exercise to lead the discussions on the question corresponding to the table, kicking-off the discussion in each new group arriving at the table by summarising the key points discussed by the previous group. In that way, each group could build upon and enrich the conclusions reached by the previous groups on the same question.

The overall atmosphere was very dynamic and constructive. Group members actively engaged in lively discussions and shared their own experience, opinion and suggestions. After participants had had the opportunity to discuss all four topics and the exercise was finished, the group leaders presented in plenary the main points discussed at each table. The main conclusions reached for the four discussion topics are presented below.

Drivers for alert and sentinel approaches and monitoring systems suitable for the detection of new WRDs

The main drivers that the participants agreed to be key for an alert and sentinel system to be successful were:

- Legislation – this is a strong driver even more important than funding. The example of Italy was discussed where there is a legal instrument according to which doctors have the obligation to report
- Standardisation of the data gathered
- Harmonisation of systems
- Low threshold – i.e allowing reporting of unclear health complaints that are potentially caused by work

The participants also considered the following points to be important drivers:

- Link to prevention – a key success factor to keep the systems running. This can provide the economic argument/business case as it justifies the need of such systems and shows their added value.
- Combined bottom up/top down approach - from physicians and representatives who are at the bottom, to the government, which is at the top and vice versa
- Expertise – in particular for the assessment of work-relatedness, and for workplace inspections
- Sound methodology to assess the captured signal
- Success stories/ best practices – should be shared and learnt from.
- Credibility of the system owner – a system should be maintained by a recognised (OSH) body

Experts from Anses (France) gave examples of their systems with some of these features. One of them is RNV3P, which has its own coding thesaurus that enables standardisation and harmonisation of data. Another example is OccWatch, an online platform that allows the

reporting of cases of new/emerging WRDs and the search for similar cases in other countries. This system is based on a strong network between occupational health physicians within France and international collaboration with specialists from other countries, mainly through the MODERNET network.

An additional point mentioned was the context in which the system is placed and that will, to a different extent, affect the possibility to implement the above mentioned aspects.

Discussion around drivers of the monitoring systems also resulted in listing the actors who play a crucial role in the implementation and maintenance of a system. These actors are:

- Government
- Companies
- Experts
- Reporters

Interestingly, participants argued that companies could also act as a barrier as their interest does not always work in favour of the detection and monitoring of new work-related health risks.

Finally, participants discussed drivers for the monitoring of specific diseases and sectors. They concluded that the nature and characteristics of certain groups of diseases make their monitoring more or less difficult. For instance, acute diseases and some diseases related to exposure to chemical substances allow a more objective assessment of exposure and, consequently, of work-relatedness. This was seen to be more difficult in the case of musculoskeletal disorders and mental ill-health. Participants considered the establishment of clear assessment criteria as a possible step forward, especially important in the case of work-related mental health problems which are on the increase.

In terms of sectors, participants concluded that awareness of new WRDs may be higher in certain sectors, such as health sector, which may facilitate the monitoring. In addition, having homogeneous exposure conditions among a group of workers is a facilitator for monitoring of work-related risks and diseases.

Finally, an added value of alert and sentinel systems was that they can provide data on self-employed who are otherwise barely covered by monitoring systems.

Obstacles to alert and sentinel approaches and monitoring systems for the identification of new WRDs

The following points were considered to be obstacles:

- **Narrow case definition**

Participants agreed that the case definition determines the sensitivity of the system and the specificity of the captured cases. A narrow case definition implies high specificity but also a high risk of missing cases of new WRDs due to its low sensitivity. Therefore, high sensitivity was seen to work more in favour of capturing new risks. Alternatively, when multiple systems are in place, they can produce complementary signals (more specific versus more sensitive signals) which can then be integrated and used for different purposes.

- **Lack of reporters**

This point was illustrated with two essential questions: 1) Who should report to a system? 2) How to keep reporters motivated to participate?

Time constraint was identified as the main obstacles for reporting physicians, due to increasing demands in their daily clinical practice. Therefore delegating the reporting task to other medical professionals, such as nurses, could be a solution. The example of the UK system THOR was mentioned, where this kind of delegation is allowed. In addition, the number of *occupational* physicians is often too limited to have a representative reporting source. Consequently, general practitioners also represent a good supporting group of reporters, as long as they are aware of work-related health problems and are willing to collaborate with occupational health specialists in recognising and identifying cases of WRDs.

- **Lack of exposure data**

The lack of (adequate) exposure data assessment was listed as a common obstacle. There are several good practice examples that can be learnt from, such as the three systems presented above (THOR, RNVP3 and Sensor-Pesticides).

- **Lack of involvement from industry**

As previously mentioned, industry was seen as a potential driver but also as a possible obstacle to monitoring of new WRDs. Possible reasons why industry may hinder the provision of data could be potential conflict of interest as well as the will to avoid a potential hype due to media involvement. Therefore, it is necessary to put conditions in place for industry to be able to “safely” report events.

- **Insurance-driven systems**

Building up on the issue of case definition, insurance-driven systems were seen as an obstacle as in general reporting cases in such systems requires a clear establishment of work-related causality, which limits the ability to capture new WRDs.

- **Lack of awareness**

Awareness of WRDs in general as well as of new/emerging risks is essential. There is a need to raise awareness at all levels, from the reporting parties to the governing bodies to provide the necessary financial and legal support for these systems.

- **Lack of harmonisation between systems and countries**

Participants supported the need for better harmonisation of case definitions and other important features of monitoring systems. This would allow more comparable and uniform data. The MODERNET network has already taken a step forward in internationalisation of monitoring work-related health risks and diseases and could be extended to more countries.

The link with prevention

Discussion took place around the level of evidence of work-relatedness necessary to trigger an alert and preventive action. There could be different levels of alert, depending on the characteristics of the captured signal, leading to different types of preventive actions and reaching different types of actors, from the shop floor to the policy level. While a reported case should trigger secondary prevention, regardless of the strength of evidence about work-relatedness, stronger evidence about work causality might have to be established to initiate primary prevention.

The participants listed some of the prerequisites of a system to improve its link with prevention:

- a learning system: regular evaluations should allow to look back and learn from success and failures
- the actors involved in the system should be reliable, credible, reputable
- good communication
- multidisciplinary team
- independent and long-term funding allowing stability of the system
- both partnership with, but also independence from industries and organisations that could present a conflict of interest (such as insurers)
- a systematic approach
- transparency, access to all reported cases
- good use of external data sources - for example the OCCAM system in Italy links cancer data from hospital registers with data from pension systems in order to have data on sectors of activity
- data security

The participants identified the main actors to involve in order to ensure a good link between the monitoring systems and prevention:

- a reference body for workplace prevention, such as labour inspectorate – for example the RAS system in Norway is owned by the Labour Inspectorate and was seen as a good example of system having a direct link to prevention
- policy makers
- OSH practitioners
- workers
- clinicians
- scientists
- statisticians
- bodies outside OSH – for example in the USA, the Environmental Agency uses information generated by Sensor-Pesticides to decide on labelling of products

Finally, some country-specific issues were raised by various participants with different national backgrounds:

- in Hungary and Bulgaria, under-reporting, financial conflict of interest, poor IT system, lack of motivation to report among physicians who are not specialised in occupational medicine were some issues
- in Italy, the issue of limited funding was seen as a limitation
- in France, some regional improvements are not well transferred to the national level and poor primary prevention was mentioned
- in Germany, data protection was seen as an issue
- in the Netherlands and Poland, under-reporting by occupational physicians was mentioned
- in Finland, the collaboration between different actors was raised as an aspect that should be improved
- in Slovakia, the inability to monitor health of workers who work abroad was reported

Alert function of systems

Different levels of alert were discussed. A possible approach is the one implemented in the French system RNV3P, where:

- Level 1 of alert is derived from data which are not specific and therefore is shared only within a limited group of internal experts;
- Level 2 is triggered when the signal becomes more specific and it is then shared within a broader group of experts;
- Level 3 activates wide dissemination of information at the national level, involves different actors and results in preventive actions.

The following points could improve the alert function of systems:

- make the system independent from compensation
- gather more information about exposure
- provide high quality data
- integrate more IT functions, such as automatic reporting and algorithms
- use notification guidelines

The importance of learning from other countries and sharing good practice approaches was also emphasized. For instance, experts from Italy have implemented the MAREL system based on the approach developed by their colleagues in France. For countries where there is no alert and sentinel systems, sharing best practice and success stories helps to make the case for such systems, or at least to support the integration of alert and sentinel-like function into existing monitoring systems.

High quality of data and exposure assessment were pointed out as essential to ensure a good alert function. High data quality data in this context refers to a reliable exposure data (such as description of workplace factors, protective equipment used, etc.). In other words, it is essential to clearly describe all variables that play a role in the establishment of the work-relatedness, but without narrowing a case definition itself.

One of the possible approaches towards the detection of new work-related health risks and diseases is the identification of high risk sectors/ industries. This approach is implemented in the Italian system OCCAM, specifically designed for work-related cancer. One of the concrete examples of a new link between exposure and WRD captured by this system is breast cancer identified among night shift workers in Lombardy (Italy). These findings were presented to the regional assembly of occupational physicians and, as a result, instructions were given to minimize such exposure and to adopt safer patterns of shift work. Moreover, there was the indication to remove from shift work all workers previously diagnosed with breast cancer because these workers are more vulnerable to exposure with regard possible recurrence of the disease, and exposure to risk factors may negatively affect the illness prognosis.

Finally, some gaps in terms of alerting on new WRDs were mentioned, such as the lack of adequate systems alerting on work-related mental health problems. Also, many countries have no alert system in place. Participants recommended that these countries put in place a good network of physicians well trained to recognise possible (new) work-related diseases as a bridging solution, or integrate an alert and sentinel-like function into existing monitoring systems at the examples of some systems described in EU-OSHA's literature review.

Conclusions

Lode Godderis summarised the key aspects that emerged from the discussions during the workshop. Firstly, he pointed out the need to share success stories, strengthen international collaboration and networking. Sharing success stories does not only help learning from each other, it also helps making the "business case" for alert and sentinel systems. Secondly, he emphasized the importance of having a legal basis for the monitoring of work-related diseases, this was seen as a key driver to the stability and success of such systems. He concluded on the importance to accept a certain level of uncertainty related to the determination of work-relatedness of cases, and to allow "low-threshold" systems in order to better detect new and emerging WRDs. He concluded on the need to learn and improve the systems over time.

Emmanuelle Brun closed the workshop, thanking the participants for their very active contributions and productive group work. This generated useful insights into various alert and sentinel systems and approaches for the detection and prevention of work-related diseases. It is important to promote information exchange and cooperation between systems and their actors at national, EU and international level, and this is what EU-OSHA seeks to contribute to through this project and workshop. Sharing best practice also helps actors in countries where there is no alert and sentinel systems to make the case for such approaches or, as an alternative, to integrate successful alert and sentinel features into existing monitoring systems. Emmanuelle Brun emphasised the importance of the effective link to prevention as key to the success of alert and sentinel systems. This was also an added value contributing to the "business case". Improving the visibility of alert and sentinel systems was another crucial aspect to their long-lasting success, and it was seen as an important motivating factor for reporters, key actors in such systems. Some gaps and challenges to address were the generally weak link to workplace exposure data - important to strengthen systems' reliability and evaluation of work-relatedness – and the poor coverage of work-related long-latency diseases and mental health disorders.

The outcome of the workshop will be incorporated into the final project report and will serve as a basis for discussions at a final seminar with policy-makers at EU and Member State level in January 2018. Through this work, EU-OSHA wishes to encourage the development of alert and sentinel systems in the EU, the overall objective being to improve the visibility and prevention of work-related diseases, independently from the recognition and compensation of occupational diseases.