



MEETING REPORT

Scientific Consultation Group Second meeting

Stockholm, December 2008

ECDC MEETING REPORT

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Stockholm, 2–3 December 2008



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Abbreviations

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| ADAPTE | ADAPTE process for the adaptation of guidelines |
| AGREE | Appraisal of Guideline Research and Evaluation |
| AIDS | Acquired Immunodeficiency Syndrome |
| DG Research | Directorate-General for Research |
| DG SANCO | Directorate-General for Health and Consumers |
| EC | European Commission |
| ECDC | European Centre for Disease Prevention and Control |
| EMRC | European Medical Research Councils |
| EMSTP | European Medical Scientific Training Programme |
| ESCAIDE | European Scientific Conference on Applied Infectious Disease Epidemiology |
| EU | European Union |
| FP7 | Seventh Framework Programme |
| G-I-N | Guidelines International Network |
| NICE | National Institute of Health and Clinical Excellence |
| OECD | Organisation for Economic Cooperation and Development |
| PYLL | potential years of life lost |
| QALY | quality-adjusted life years |
| SAU | Scientific Advice Unit at the European Centre for Disease Prevention and Control |
| SCG | Scientific Consultation Group |
| WHO | World Health Organization |

Executive summary

The pan-European scientific societies, federations, associations and organisations (hereafter called 'learned societies') represented in the Scientific Consultation Group (SCG) stand for a wide range of scientific interests and contribute to policy development in the European Union. ECDC wants to establish close relations with the learned societies in the SCG in order to advance public health in Europe through networking and cooperation.

The first objective of the second SCG meeting (2–3 December 2008) was to exchange experiences and views on research priorities in regard to infectious diseases in Europe and discuss how to identify and prioritise topics for future research on infectious diseases, based on expected health threats. A second objective was to discuss the development of guidelines for infectious diseases in Europe and start brainstorming about possible ECDC contributions.

It was agreed that one of ECDC's strengths lies in networking with scientists and/or representatives of learned societies from the EU and the rest of Europe. The added value of networking with learned societies lies in their strong connection with research institutions all over Europe through national societies and individual members, which provides direct access to source information.

Both ECDC and the learned societies are committed to continue their consultation processes. ECDC is considering participation in annual conferences and other events hosted by the learned societies. The learned societies want to continue their work with ECDC via the networks that were established during the meeting. The meeting participants recommended that ECDC should continue to hold annual SCG meetings, as they help to connect ECDC with the European research community.

The EU Member States play an important role when defining research priorities for infectious diseases, as they have established funding mechanisms that are more important to researchers than EU sources of funding. This puts countries in eastern and southern Europe at a disadvantage since there are, on average, fewer state funds available for medical research. At current, public health research is more focused on surveillance and epidemiology than prevention and control, and there appears to be a lack of attention in regard to the determinants of infectious diseases. In order to define research priorities for infectious diseases, it is necessary to anticipate future health threats. ECDC has identified a series of diseases which may emerge as result of climate and demographic change, globalisation, and changes in infective agents. WHO also provides guidelines for research priorities, and the European Medical Research Councils outlined priorities to improve medical research in Europe.

The meeting participants agreed that ECDC should guide the prioritisation process of future research efforts in the area of infectious diseases in Europe. ECDC should focus on the public health dimension of infectious diseases and on research on determinants (e.g. climate and socio-economic factors), rather than initiate disease-related clinical research. Assessing the burden of infectious diseases and their determinants could be a first step.

Through close collaboration with the Directorate-General for Research and the Directorate-General for Health and Consumers, ECDC should promote the inclusion of specific topics into the EC's research agenda. ECDC can call on the network of pan-European learned societies and their member organisations to inform the research communities in the Member States on relevant research issues.

In order to ensure that a set of developed guidelines is actually used by the target group, the stakeholders must be involved when developing guidelines. The finalised guidelines have to be clear and concise, and adhere to the values of the users. Also, scientifically proven methods of guideline development should be used, e.g. the AGREE methodology. ADAPTE provides information on how to adapt existing guidelines to local needs.

ECDC could provide assistance by maintaining databases on existing guidelines and evidence, and by providing support to Member States. Learned societies often play a rather prominent role in guideline development and could provide technical expertise.

Global and evidence-based guidelines are powerful tools for improving the quality of public health interventions in Europe. The SCG agreed that ECDC could play a significant role by providing support to infectious disease guidelines.

During the meeting, some participants expressed their reservations towards unified pan-European guidelines. Guidelines have to be owned locally and have to address local needs. One reply was that European guidelines could be developed as core guidelines, which are then localised by Member States using the ADAPTE methodology.

ECDC could establish a repository of guidelines on infectious diseases, evaluate these guidelines and provide comments and recommendations for improvement. The learned societies could then disseminate them. There is no established standard for the implementation of guidelines on infectious diseases in the EU. ECDC could evaluate guideline implementation in Member States and make recommendations on how to further improve implementation.

Introduction

This report reflects the proceedings of the second meeting of the Scientific Consultation Group (SCG) of the European Centre for Disease Prevention and Control (ECDC), which was held on 2 and 3 December 2008 in Stockholm. The first meeting of the SCG was conducted in February 2007¹. SCG's December 2008 meeting at ECDC in Stockholm was attended by 36 representatives from learned societies and four ECDC staff members.

The mission of ECDC is to identify, assess and communicate current and emerging threats to human health caused by infectious diseases. By working with experts throughout Europe, ECDC pools Europe's health knowledge, so as to develop authoritative scientific opinions about the risks posed by current and emerging infectious diseases. The ECDC's Scientific Advice Unit (SAU) is entrusted with the task of providing independent and high-level scientific assessments on infectious diseases as a basis for EU public health decisions in this area.

The pan-European scientific societies, federations, associations and organisations (hereafter called 'learned societies') participating in the Scientific Consultation Group (SCG) represent a wide range of scientific interests and contribute to policy development in the European Union.

ECDC wants to establish close relations with the learned societies in the SCG in order to advance public health in Europe through networking and cooperation. The SCG should complement current ECDC initiatives by collaborating with policy makers and public health institutes in the Member States as well as individual experts in Europe. The learned societies represent national societies or organisations, and individual members, and are therefore well connected with the research community in all European countries. By bringing ECDC and these societies together in an organised forum, it is expected that the combined capacity and knowledge will benefit and strengthen European public health.

The main objective of the second SCG meeting (2–3 December 2008) was to exchange experiences and views on research priorities in regard to infectious diseases in Europe, and to discuss how to identify and prioritise topics for future research on infectious diseases in view of expected health threats. A second objective was to discuss the development of guidelines for infectious diseases in Europe and start brainstorming about possible ECDC contributions. These two areas were identified based on earlier consultations with the learned societies in the spring of 2008.

During the introductory session of the meeting, Johan Giesecke, head of ECDC's Scientific Advice Unit (SAU) and Jan Semenza, section head Future Threats and Determinants, gave background information on SAU and the SCG's role in enhancing ECDC's performance (see Annex 1). Further presentations explored the above-mentioned topics in greater detail.

¹ See http://ecdc.europa.eu/documents/pdf/PH%20_Networking.pdf

1 Research

Session 1: Present practices of setting research priorities for infectious diseases in Europe

Highlights of the presentations

During the first session, the participants exchanged views and opinions on relevant research topics for infectious diseases as well as on the process of setting research priorities. Discussed questions included whether research in the European Union (EU) covered the appropriate areas of research, particularly in view of existing and future threats from infectious diseases, and whether all relevant parties are consulted when defining research priorities.

Koos van der Velden (Radboud University, Nijmegen, The Netherlands) gave an overview of current research on infectious diseases in the EU. He conceded that it is very difficult to gain insight into the funding mechanisms for research in the EU, not least because of the fragmented financing structure: Member States have their own systems for commissioning research. Although there is reasonable knowledge on how research is commissioned at the European level (through the European Commission), the diversity and volume of research funded by the EU and the Member States means that tracking research funding and outputs can be a challenging task. Some of the research funded by the EC is occupied with infectious diseases, but the determinants of those diseases are largely ignored, and so are the underlying health systems. An analysis of funding shows that northern and western European countries spend much more on health research than southern and eastern European countries. Public health research is much more concerned with surveillance and epidemiology than prevention and control. There is little knowledge about impending threats, e.g. climate change or zoonoses spread through global trade. The speaker argued that there should be more links between research institutions/local public health authorities and the public health practitioners that actually deliver public health measures. This would speed up the flow of relevant data to primary researchers and allow public health practitioners to feel more connected with the research agenda and the associated policy changes arising from such research.

Cornelius Schmaltz (Directorate-General for Research, EC) gave an overview of the FP7 research programme, its priorities and the actual research currently underway. The projects selected and implemented can be found on the Cordis website. Examples of research activities cited by Mr Schmaltz included antimicrobial drug resistance, HIV, malaria, tuberculosis, new and re-emerging diseases, and neglected infectious diseases.

The EC research programme is established in consultation with stakeholders in the Member States. A work programme is drafted annually, leading to requests for proposals from research groups. The EC has defined criteria for eligibility, for the assessment of capacities of research groups, and for the assessment of quality of proposals. The EC aims for transparency and objectivity in the selection of proposals.

Box 1. Present practices of setting research priorities for infectious diseases in Europe

The EU Member States play an important role in setting research priorities for infectious diseases, as they maintain their own funding mechanisms. Direct funds from Member States may be more important to researchers than European sources of funding. This is a disadvantage for research in eastern and southern Europe, where less money is available for medical research. The EC formulates its research priorities based on consultations with stakeholders.

Presently, public health research covers more surveillance and epidemiology than prevention and control. There is not enough attention to determinants of infectious diseases.

ECDC promotes research on infectious diseases, but does not have the capacity to conduct extensive research itself.

Discussion

In the discussion following the presentations it was noted that in public health there is a difference between basic research and translation research that supports the implementation of new approaches or interventions in disease prevention and control. The basic research hardly touches upon areas such as determinants of infectious diseases; it is primarily descriptive in its approach. Especially in the area of public health practice, there is insufficient research. Therefore, the evidence-base of public health interventions is questioned from time to time. Experiments and development of best practices are considered applied research and are therefore funded by the European

Agency for Health and Consumer Protection (under the Directorate-General for Health and Consumers), not under the FP7 programme.

Also mentioned was the imbalance in research between new and old Member States. The quality of proposals and research teams suggests that newly established research centres are disadvantaged. Strengthening research in new Member States through international networking could be helpful, and the learned societies could assist; the societies could even submit research proposals to the FP7 research programme.

Participants felt that ECDC could play a more prominent role. Johan Giesecke, head of ECDC's Scientific Advice Unit, concluded that ECDC could help establish links between research needs, research competencies, and research funding. The learned societies could advise ECDC in this area.

Session 2: Setting research priorities — long-term perspectives

Presentations

Jonathan Suk (ECDC) gave an overview of potential threats to public health from infectious diseases in Europe. Changes in environment, demographics and behaviour may result in epidemiological changes.

Antimicrobial resistance may increase due to imprudent use of antibiotics. Certain diseases (HIV, STIs, TB) may spread further and/or may become more resistant. Vector-borne diseases may increase further due to climate change and changes in land use. Food-borne diseases may increase due to global trade and the spread of vectors and agents. Certain illness spread more easily among elderly people living in institutional settings (e.g. nursing homes), and major outbreaks of influenza may erupt. Another potential problem lies in the reduced attention to preventive measures, e.g. vaccination fatigue. Finally, we may be confronted with completely new diseases, as we were in the past (HIV, BSE, and SARS).

Jaap Koot (Public Health Consultants, The Netherlands) gave a short overview of methodologies for setting health research priorities. Whereas academia, industry and charity use internal procedures when setting priorities, the EC and national research councils have a more public and transparent way of defining priorities. The World Health Organisation has compared methods and has formulated recommendations for setting research priorities. These recommendations may be also helpful for Member States.

Martin Röllinghoff (European Science Foundation) presented a White Paper published by the European Medical Research Councils and outlined some of the priorities aimed at improving medical research in Europe: investing in people, infrastructure, and information technology. Research should be in centres of excellence or competitively commissioned. Above all, research funds should be increased, so Europe could become a world leader in medical research.

Box 2. Setting research priorities — long-term perspectives

In order to define research priorities for infectious diseases, it is necessary to anticipate future health threats. ECDC has identified a series of diseases that may emerge as result of changing determinants, for example climate change, demographic changes, globalisation, and changes in infective agents.

WHO is providing guidelines for the formulation of priorities, based on experiences with different methods, which could be used by Member States. The European Medical Research Councils outlined priorities for improving medical research in Europe, so Europe could become a world leader in medical research.

Discussion

Basic approaches when setting priorities: Principles

There are two approaches when setting priorities for research: the bottom-up approach, whereby researchers suggest research topics and try to persuade funders of their value, or the top-down approach, whereby priorities are decided upon by policy/political preference and then translated into nationally and/or EU-funded research calls. These two approaches should be balanced so as not to stifle initiative.

Priorities in Member States

In most countries in Europe, health research councils define research priorities, often via consultative processes. Although these councils may advise on scientific grounds, there is always an element of political decision-making when setting research priorities. National and European learned societies could therefore lobby health research councils. ECDC's mandate and capacities are limited in regard to directly influencing funding decisions at national

levels, but national and pan-European learned societies could utilise the SCG network for international consultations with ECDC on prioritisation issues.

European Union

The European Commission and the European Parliament highlight relevant public health issues, particularly in those areas where the EU could take a global lead in solving them. Infectious diseases are definitely important European issues. ECDC could act as a catalyst in this process by creating a platform where scientists could share ideas and highlight gaps and priorities in infectious diseases research. ECDC could then present these ideas to funding agencies and lobby for decisions on future fund allocation. ECDC could act as an interface between the bottom-up and top-down approaches in research.

Topics for research priorities

There is a need to set clear criteria for the selection of topics. Some suggestions are listed below.

Burden of infectious diseases, determinants, best practices in interventions, and cross-border strategies

Firstly, the burden of infectious diseases is important. Morbidity, mortality, costs, potential years of life lost (PYLL) and quality-adjusted life years (QALY) could be used as prioritisation criteria. Epidemiological investigations should underpin the selection, despite the fact that studies on specific infections are complex and expensive.

Secondly, in selection of research topics we should take into account the determinants of infectious diseases: socio-economic, environmental, lifestyle, migration and globalisation, and health systems.

Thirdly, the feasibility of interventions could play a role in the selection of research topics. It is necessary to research the overall impact of proposed interventions, including knock-on negative impact on others. There is hardly any knowledge on topics such as behavioural change and other non-therapeutic preventive actions.

It is also advisable to explore simple interventions that yield good results.

At the European level, the meta-analysis of best practices could result in intervention models that could be applied across all disease-control programmes. ECDC could add value by collecting pertinent examples of successful interventions in a library.

Finally, Europe-wide implementation strategies need to be studied in depth. During the discussion, the topic of inter-operability (applying health systems across borders) was mentioned. Research on the implications of health system variance across the EU would be helpful, as would be mechanisms to improve inter-operability and international collaboration in disease control programmes.

Specific topics

Additional topics that need attention are the human/animal interface, vector borne diseases, migrant health, and behavioural factors in vaccinations (fatigue). Molecular epidemiology research and translational research in this area is growing and needs attention.

Coordination

ECDC could also serve the research community by establishing a database with (unpublished) research findings, ongoing research and research opportunities (e.g. links to relevant sites where requests for proposals are published). ECDC could support collaborative research efforts by providing a platform for research organisations through which to interact and contact each other. Newly established research groups in new Member States may have a stronger need for such support than institutions in Western Europe. Researchers in new Member States could also benefit from focused support of educational activities, both nationally and internationally.

2 Guidelines on infectious diseases

Session 3: Development of guidelines and standards

Presentations

Niek Klazinga (OECD) gave an overview of the state of affairs in healthcare guideline development in Europe. Over the last 30 years, guidelines have gone through several stages of development and are now mostly implementation-based. Several well established methodologies are available, e.g. the one used by the AGREE (Appraisal of Guideline Research and Evaluation) Collaboration, an international partnership of researchers and policymakers, and the ADAPTE guideline adaptation process.

Presenting evidence — and presenting it in a transparent way — is essential when producing guidelines. This is achieved much more easily when working on clinical guidelines than public health guidelines. The strength of recommendations is another important issue in guideline development. Several rating methods are available, and there are unified taxonomies for the strength of recommendations based on a body of evidence. Yet even if evidence is limited, there may be good reasons for issuing strong recommendations. In public health guidelines, evidence may be limited and obtained from similar diseases, but recommendations can still be strong, e.g. in the case of infectious diseases that spread quickly.

Sara Twaddle (SIGN, G-I-N, Guidelines International Network) pointed out some barriers to the implementation of guidelines. According to her experience, guidelines are only adhered to if they are widely disseminated and communicated with the target groups. All means of communication must be used to bring them to the attention of the respective target groups.

Practitioners are very critical people. They do not accept guidelines of poor quality or with low levels of evidence. Target groups should be included in the formulation of guidelines to instil a sense of ownership. Cultural and financial factors may play a role in acceptance. Guidelines should be simple and their implementation should draw on the practitioners' knowledge and skills.

It is important that patients accept the developed guidelines, and this should be kept in mind during the preparation phase. Finally, guidelines need to be updated frequently.

International collaboration on guideline development may assist in collecting evidence, in learning from guidelines developed at other locations, and in exchanging experiences on how to overcome implementation barriers. G-I-N offers a platform for information exchange on these topics.

Howard Needham (ECDC) explained ECDC's role in guideline development. ECDC is mandated to provide scientific advice. Initially, ECDC developed guidelines in a more prescriptive way (e.g. for avian influenza), but now ECDC is primarily offering expert views and scientific background information. Occasionally, ECDC encountered resistance to its more prescriptive guidelines, as they were interpreted as interference in the area of risk management.

Given this background, some possible roles for ECDC in this context were presented, including developing an inventory of evidence to be used in guideline development, or establishing a database with existing guidelines. ECDC could validate and subsequently endorse guidelines developed by other organisations. ECDC could also develop guidelines on health issues that have an EU-wide importance and require a standardised approach across Member States.

Inge Gyssens (ESCMID) elaborated on the role of pan-European learned societies in guideline development. Nearly all infectious diseases are covered by one or more organisations. Often the societies have developed (core) guidelines in their areas of work. When probing the necessity of guideline development, ECDC could ask advice from the relevant learned societies. In addition, learned societies could provide the names of experts who could then contribute to guideline development and provide general feedback.

Learned societies can play a role in dissemination, as they have an extensive network of member organisations. They could form a parallel network of dissemination, in addition to the network of public health institutions in the Member States. Finally, the societies could assist ECDC in measuring compliance and analysing implementation barriers.

Box 3. Guidelines on infectious diseases

Over the years, scientifically sound methods for the development of guidelines have been put in place, e.g. the AGREE methodology. The ADAPTE methodology provides information on the adaptation of guidelines to local needs. Using these methodologies ensures quality. However, it is rather difficult to assess the weight of the evidence base when developing public health guidelines, as they are primarily based on best practices.

A series of measures must be taken to ensure that developed guidelines are accepted and used by the target group: stakeholders have to be involved in the guideline formulation process, the resulting guidelines have to be simple and concise, and have to adhere to the users' value system.

Although ECDC does not have a role in the formulation of national guidelines on infectious diseases, it could provide assistance by maintaining databases on evidence and existing guidelines, and by providing capacity building to those who request assistance.

Learned societies often play a prominent role in guideline development and could provide technical expertise.

Discussion: The role of European institutions in guideline development

According to the meeting participants, ECDC's mandate should not be unnecessarily restricted in respect to guideline development. In cases of public health threats across Europe, ECDC should play a more proactive role.

Mapping exercises

ECDC could perform a role in a mapping exercise of existing guidelines in the EU, and in identifying gaps and inconsistencies. Part of the mapping could include an inventory of implementation barriers to public health guidelines and an assessment of reasons that lead to opposition towards European guidelines.

Most guidelines concentrate on clinical care, few on public health. ECDC could do more research in best practices, identify which countries have successful public health guidelines, get good compliance, and have a positive impact.

ECDC could perform a mapping exercise of resources and processes with regard to guideline development at the EU and Member State levels as well as in learned societies. ECDC could develop a comprehensive database of public health-related guidelines (repository on infectious diseases).

Technical support in guideline development

ECDC could experiment with guideline development for infectious diseases, particularly with those Member States that express a need for technical assistance. ECDC could assume a coordinating role. Collaboration with WHO, OECD and other organisations should be considered.

ECDC could also validate guidelines at the request of Member States and conduct research on how to make the Member States adopt European guidelines. Monitoring and evaluation should be developed in parallel with the guidelines.

The role of the SCG

The Scientific Consultation Group could be institutionalised (including learned societies in public health) and assist in the development of a methodology of public health guidelines, acting as sparring partner for ECDC. The public health societies should become more involved in the SCG.

Learned societies and ECDC: Collaboration in the formulation of guidelines

In an EU public health guideline programme, knowledge about the burden of diseases would assist in the identification and prioritisation of health topics for which guidelines have to be developed². There should be guidelines for diseases with the highest burden. Learned societies could assist in identifying gaps. It would be helpful if ECDC had a platform that would facilitate the exchange with learned societies. Using the same platform, experts could suggest who should play a role in the development of guidelines.

² Research in order to gain insights into the actual burden of disease was also mentioned during the session on research priorities.

Guidelines at the European level

When developing guidelines it should be clear what the added value of European guidelines is. European institutions could make a helpful contribution when local interests (politics) impede national development or when coordinated international action is required. However, the necessary funding for guideline development would then have to come from the EU.

Dissemination

The learned societies could play a role in dissemination. They could distribute guidelines through member societies and through experts in relevant working groups or committees. This approach would boost the spread and acceptance of guidelines and improve ECDC's relation with national representatives.

ECDC is considering participation in annual conferences and other events hosted by the learned societies in order to present its goals and options for collaboration with the respective learned societies. By getting to know ECDC and its objectives better, the learned societies may be more willing to provide assistance.

3 Closing remarks

Johan Giesecke stated that ECDC's mandate is in public health and infectious diseases, and that ECDC would concentrate on research and guideline development in those areas. He saw a clear link between research topics and guidelines, as research can identify areas for which guidelines need to be developed and can provide the necessary evidence for scientifically sound guidelines. Research on best practices of guidelines is also important for ECDC in order to give adequate advice to Member States.

The Scientific Advice Unit appreciated the exchange with learned societies and invited them to contribute to the formulation of the work plan for 2010.

4 Conclusions

Introductory presentations given on both days set the stage for small group and plenary discussions on the role of ECDC in research on infectious diseases in Europe and the development of evidence-based guidelines for infectious diseases and public health.

ECDC's networking efforts

It was agreed that one of ECDC's strengths lies in networking with leading scientists and/or representatives of learned societies from the EU and the rest of Europe. The added value of networking with learned societies lies in their connection with research institutions all over Europe, which provides direct access to source information.

Meetings like the one with the Scientific Consultation Group offer ECDC an opportunity to hear the voice of the European research community. Both ECDC and the learned societies are still developing ideas on how to structure the SCG.

ECDC's role in the formulation of priority research topics

Meeting participants agreed that there is a role for ECDC in guiding the process of setting priorities for future research in Europe in the area of infectious diseases. ECDC could emphasise the public health dimension and conduct research on the determinants of disease (e.g. in regard to climate change and socio-economic factors), rather than disease-related clinical research. As a first step in this process, the burden of infectious diseases and their determinants should be assessed.

Through close collaboration with the Directorate-General for Research and the Directorate-General for Health and Consumers, ECDC will advocate that specific research topics should be added to the EC's research agenda. ECDC could use the network of Pan-European learned societies and their member organisations to inform the research communities in the Member States on relevant research topics.

ECDC's potential for strengthening the methodology for developing public health guidelines

Worldwide, evidence-based guidelines are recognised as strong tools for improving the quality of public health interventions in Europe. A guideline development process based on AGREE and ADAPTE methodologies is well suited for the development of clinical guidelines, but may need further refinement for public health guidelines. The SCG agreed that ECDC could play a significant role in this field. The participants voiced the need for an internationally recognised body, such as ECDC, to provide support when developing infectious diseases guidelines, particularly within the framework of public health.

Developing guidelines for infectious diseases: ECDC's practical support

ECDC could use its expertise on disease burden and potential threats to identify areas where guidelines need to be formulated. ECDC could set up a clearing-house of evidence for EU guideline developers, complete with a database of relevant documentation. The learned societies could provide experts or feedback for all these activities.

During the meeting, some participants expressed their reservations towards unified pan-European guidelines. Guidelines should be owned locally and address local needs. One response to this problem was that European guidelines could be developed as core guidelines, which are then localised with the ADAPTE methodology. Several participants stated that there is the need to encourage new Member States to develop, adopt and implement public health guidelines.

ECDC's implementation support

ECDC could establish a repository of guidelines on infectious diseases, evaluate them and provide comments and recommendations for improvement. The learned societies could then disseminate them. There is no established standard for the implementation of guidelines on infectious diseases in the EU. ECDC could evaluate guideline implementation in Member States and make recommendations on how to improve implementation.

The future of the SCG

Both ECDC and the learned societies are committed to continue their consultation processes. ECDC is considering participation in annual conferences and other events hosted by the learned societies. The learned societies want to continue their work with ECDC via the networks that were established during the meeting. The SCG meeting participants recommended that ECDC should continue to hold annual SCG meetings, as they help to connect ECDC with the European research community.

Annex 1. Presentation summaries

Summary of presentations: 2 December 2008

Introduction session

Johan Giesecke, Head of the Scientific Advice Unit, ECDC: The Scientific Advice Unit

ECDC's Scientific Advice Unit (SAU) follows five main strategies. The Scientific Advice Unit:

- acts as a public health research catalyst;
- promotes, initiates and coordinates scientific studies;
- produces guidance, risk assessment, scientific advice;
- aims to become a prime repository for scientific advice on communicable diseases; and
- provides microbiological laboratory support.

In this context, SAU organises scientific meetings on public health issues for researchers, funders and stakeholders, for example the Annual European Scientific Conference on Applied Infectious Disease Epidemiology (ESCAIDE).

SAU maintains an extensive database of scientific information and provides responses to questions asked by the European Parliament or the European Commission.

Jan Semenza, Scientific Advice Unit, ECDC: The purpose of the Scientific Consultation Group

The mandate of ECDC is to protect human health from communicable diseases through the prevention and control of human disease and to ensure comprehensiveness, coherence and complementarity of action.

The Scientific Consultation Group (SCG), consisting of pan-European learned societies, associations, federations and organisations, could provide a long-term framework to advance public health in Europe through networking and cooperation. The SCG could complement current initiatives and strengthen European public health in general. The European learned societies represent national associations, federations and organisations, and therefore achieve a wide reach.

The first meeting of ECDC's SCG was held in February 2007. A survey revealed that the societies would like to collaborate in the identification of research needs and priorities and in the development of guidelines. Furthermore, the societies would like work together in professional and public educational initiatives and advocacy. The associations suggested cooperative public health activities, e.g. surveillance, intelligence gathering, evaluation and monitoring. 57 organisations were invited to the second SCG meeting, and 36 accepted the invitation.

The first objective of the second SCG meeting was to exchange experiences and views on research priorities in regard to infectious diseases in Europe, and to discuss how to identify and prioritise topics for future research on infectious diseases, based on expected health threats. A second objective was to discuss the development of guidelines for infectious diseases in Europe and start brainstorming about possible ECDC contributions.

Session 1. Collaboration in infectious disease research

Koos van der Velden, Department of Public Health, Radboud University Nijmegen Medical Centre: Infectious disease research in Europe — an overview

In order to assess the amount of research on infectious diseases and its relevance, it is necessary to establish a conceptual framework. ECDC concentrates on public health interventions in infectious disease control. Surveillance of infectious diseases and outbreak management, primary and secondary prevention, communication and information are public health interventions that all fall under ECDC's mandate.

We could relate the disease burden in Europe with the amount of money spent on research. The disease burden of seven diseases in twelve countries in Europe 2003–2005 (source: van Lier & Havelaar RIVM 2007)³ shows that campylobacteriosis and salmonellosis have the highest incidence, but TB and HIV have the highest mortality.

³ Downloaded from: <http://www.rivm.nl/bibliotheek/rapporten/215011001.pdf>

When calculating the burden of disease (using DALYs), HIV is responsible for 38.3 % of the disease burden, TB for 35.9 % and campylobacteriosis for 10.7 %. EU-funded research on infectious diseases is based on four pillars (source: EU Research FP6 and FP7): The Europe and Developing Countries Clinical Trial Partnership receives € 400 million (with a focus on vaccines and drugs against HIV, TB and malaria); for neglected infectious and tropical diseases € 110 million are available; for emerging infections the total amount is € 90 million (mainly for influenza); and for antimicrobial drug resistance € 200 million are available. One could conclude that all important diseases are covered by research. However, funding through the Directorate-General for Research is only a small part of the total funding; there is also funding through the EU public health programmes. The Member States have their own programmes, as has the private sector. Philanthropy should not be underestimated as source of funding. It is impossible to get a thorough insight into these sources of funding, but their combined value is believed to be much higher than all EU funding combined.

Durando et al. looked at publications from July 1995 to June 2005⁴ as source of information on research activities in Europe and concluded that research on 'epidemiology and surveillance' generated significantly more publications than 'prevention and control'. This indicates the greater willingness of — or more opportunities for — researchers to count diseases rather than engage in the governmental policy areas of organisation and evaluation of healthcare. Compared to Western European countries, Central and Eastern European countries lagged behind in their research efforts.

When setting research priorities we need to focus on future threats rather than present disease patterns. One of the threats comes from zoonoses, or infectious diseases moving from animals to humans. Socio-economic factors play an important role, e.g. the risk of transmission is increased by the global trade in cattle, food products, etc. The determinants of diseases need to be investigated. It is becoming increasingly important to conduct research on health systems and their ability to handle health threats, especially at the local (municipal, district) levels.

If researchers aim at influencing policy development, they have to realise that decision-making is not only based on scientific evidence, but also on many socio-political factors. It is important that they create ownership of research questions and research outcomes among stakeholders.

Cornelius Schmaltz, Infectious Diseases Unit, Health Directorate, Directorate-General for Research, European Commission: Infectious disease priorities at the Directorate-General for Research

The Infectious Diseases Unit is one of the units under the Health Directorate at the Directorate General for Research of the European Commission.

For the FP7 research programme, € 50.5 billion are available for a period of seven years, which represents a 40 % budget increase over the FP6 programme. Of this amount, € 6.05 billion are earmarked for health research.

Areas of infectious disease research include antimicrobial drug resistance, HIV, malaria and tuberculosis, potentially new and re-emerging diseases, and neglected infectious diseases.

The Directorate-General for Research produces annual work programmes with topics in response to public health needs and new scientific/technological developments. The directorate keeps in mind the existing research capacity in the EU as well as other policy needs when drafting the work programme. During the drafting phase there are extensive consultations with other entities within the EC, with Member States, and through conferences and workshops.

The EC has defined criteria for funding eligibility, for the assessment of research groups and their capacities, and for the assessment of the quality of proposals. The EC aims for transparency and objectivity in the selection of proposals. The selected projects can be found on the Cordis website⁵.

Other FP7 programmes may also deal with infectious diseases, e.g. the integration of European national research programmes PEOPLE (implemented via a set of Marie Curie actions), CAPACITIES (research infrastructures) and IDEAS (implemented through the European Research Council, ERC).

The Directorate-General for Research is providing more information on research, conditions for application and outcomes of research on its website.⁶

⁴ Report downloadable from: <http://www.ucl.ac.uk/public-health/sphere/Publications/Infectious%20Disease.pdf>

⁵ See: http://cordis.europa.eu/home_en.html

⁶ See: http://ec.europa.eu/research/health/infectious-diseases/index_en.html

Session 2. Setting research priorities — long-term perspectives

Jonathan Suk, Scientific Advice Unit, ECDC: Health threats and research needs

In order to set priorities in health research, we need to understand current and future threats and plan our research ahead of actual changes in disease patterns. ECDC is in the process of formulating the threats of communicable disease in Europe.

There are several drivers of change in disease risks. Europe is experiencing changes in demography (aging population, migration) that influence disease patterns. There are also changes in the environment, due to climate changes and land use (urbanisation, recreation, agriculture). Trade, travel and changing lifestyles continue to change the way people live in Europe. There are still enormous socio-economic inequities in Europe, not only within countries, but also between countries and regions.

Antimicrobial resistance may increase due to imprudent use of antibiotics. Certain diseases (HIV, STIs, TB) may spread further and/or may become more resistant. Vector-borne diseases may increase further due to climate change and changes in land use. Food-borne diseases may increase due to global trade and the spread of vectors and agents. Among elderly people living in institutional settings (e.g. nursing homes), certain illness spread more easily, and major outbreaks of influenza may erupt. Another potential problem lies in the reduced attention to preventive measures, e.g. vaccination fatigue. Finally, we may be confronted with completely new diseases, as we were in the past (HIV, BSE, and SARS).

Jaap Koot, Public Health Consultants, the Netherlands; Martin Rusnak, University of Trnava, Slovakia: Criteria for setting research priorities in infectious diseases

Many scientists prefer to set their research priorities based on their interests, yet financial limitations make it impossible for them to always work this way. Agencies that commission research have their own methods for setting priorities (top-down). The private sector and charities often have clear-cut priorities. Public institutions, like the European Commission, national medical research councils or the national institutes of health have their specific methodology when setting priorities, often in consultation with stakeholders.

In April 2008, the World Health Organization organised a workshop that compared different methods of setting priorities in medical research, and later released a set recommendations.⁷

The workshop recommended that setting research priorities should adhere to principles of legitimacy and fairness. Commissioning organisations should be explicit on values. The methods and tools that are used when setting priorities and selecting research proposals have to be transparent and replicable. There should be a follow-up with regard to commitments and outcomes, as well as an appeal mechanism (decisions, clear reporting). The WHO compared three methods: the Global Forum Health Research, the Combined Approach Matrix and the Child Health Nutrition Research Initiative. These three methods are based on the size of the disease burden and the disease determinants. When setting priorities, the state of current knowledge is important, as is the feasibility of public health interventions.

From a public health perspective, research challenges in infectious diseases can be divided into four areas: basic knowledge, tools, interventions, and strategies.

We need to increase our basic knowledge about factors that determine the spread and control of infectious diseases (the 'determinants'). We need to know more about tools that can control infectious diseases, and learn how to combine tools into intervention programmes. Finally, we need to find ways to scale intervention programmes so they match national and international strategies.

From ECDC's point of view, one major question remains: What should ECDC's strategic research emphasis be for infectious diseases?

Martin Röllinghoff, European Science Foundation: The European Medical Research Councils' White Paper — 'Present status and future strategy for medical research in Europe'

The EMRC (European Medical Research Councils) is the European Science Foundation's membership organisation for all medical research councils under the European Science Foundation in Strasbourg. The mission of EMRC is to promote innovative medical research and its clinical application towards improved human health. EMRC offers authoritative strategic advice for science policy making, research management, ethics, and better health services.

⁷ See: http://www.who.int/tdr/stewardship/pdf/Priority_setting_Workshop_Summary10_04_08.pdf

In its white paper ('Present status and future strategy for medical research in Europe'⁸), EMRC proposes that the present level of funding for medical research across Europe should be increased, and that there should be enhanced collaboration between European nations and institutions. Funding should be distributed in competition through peer review and based on scientific excellence. This should result in strong basic, clinical and translational research.

Europe needs to invest in people through career track schemes and a European Medical Scientific Training Programme (EMSTP). The research infrastructure should improve through investment in national and European research institutes. Europe has to invest in post-genomic clinical medicine and in information technology. The EC and Member States should simplify regulations to facilitate research. Organisations should share research and results and stimulate public engagement about medical research and its possible impacts.

Summary of presentations: 3 December 2008

Session 3. Development of guidelines and standards

Niek Klazinga, OECD, AMC/UvA, NPHF: Guidelines, standards and evidence — an overview

Clinical practice guidelines can be defined as systematically developed statements that assist practitioner and patient decisions when determining the appropriate healthcare under specific clinical circumstances (IoM, Field and Lohr, 1992).

Guidelines spark interesting debates, as they can be discussed from several perspectives:

- individual versus societal;
- clinical versus public health; and
- professional, patient, manager versus society/policy maker.

It is important to realise that evidence, guidelines and standards are social constructs.

We can distinguish four generations of guidelines. Consensus-based guidelines appeared first in the early 1980s in national institutes of health and were based on expert views. Evidence-based guidelines started in the late eighties, using literature findings. Cost-effectiveness-based guidelines were initiated in the late 1990s by NICE (National Institute of Health and Clinical Excellence, UK), and now implementation-based guidelines are under development. With every new generation of guidelines there is an increase in maturity and a growing formalisation of development methods. The steps to be followed from topic selection to regular review are well defined. In Europe, the AGREE (Appraisal of Guidelines Research and Evaluation) methodology⁹ is used most frequently.

The use of evidence in guideline development is essential. Several evidence grading systems have been developed over the years. However, grading is not always simple, as reviewers may interpret literature differently. Therefore, standards for literature review have been developed. Cost-effectiveness is also a controversial topic: policy makers are more interested in this aspect than clinicians. Cost-effectiveness should be discussed in terms of balancing harms and benefits. Cost-effectiveness should always be transparent and clearly explained. Although evidence can be of global value, its applicability at the local level has to be weighed. The clinicians (or public health workers) who have to adhere to guidelines, also have to look at the quality of the evidence and the strength of the recommendation. In general, one would expect the strongest recommendations when the evidence is most convincing. However, when costs are prohibitive or other risks are related to the evidence (e.g. creation of antimicrobial resistance), the second-best solution may be selected.

The strength of a recommendation is the balance between the positive effects of adherence/compliance and the negative effects of non-adherence/non-compliance. In other words, if non-adherence leads to major risks for the patient or a group, a strong recommendation is justified, even if there is no major proof of benefits of the recommendation. This approach may be important for public health interventions, where evidence is not always as strong as in clinical medicine. During the development of guidelines, the process of grading evidence and of grading recommendations should be fully transparent, allowing readers to verify the evidence, and allowing replication under different circumstances.

Pan-European guidelines on public health may have their limitations. General guidelines may not be easily implemented because of the heterogeneity of European countries. It may be difficult to involve all actors, which may affect the credibility of guidelines.

⁸ See <http://www.esf.org/publications/medical-sciences.html>

⁹ See <http://www.agreecollaboration.org/intro/>

Sara Twaddle, Scottish Intercollegiate Guidelines Network (SIGN) and Guidelines International Network (G-I-N): Barriers to the implementation of clinical guidelines

The number of guidelines in PubMed is now nearly 2 500 (not counting NICE and SIGN guidelines). The development of guidelines has gone through several stages, e.g. based on expert opinion, consensus, evidence. Current guidelines are better verifiable and less biased, but a subjective element cannot be avoided when a guideline-drafting group produces recommendations. Therefore, users should be able to verify the process of formulating recommendations in order to increase their confidence in guidelines.

Guideline adaptation has become a new branch in guideline development: adapting, combining or expanding existing guidelines is helpful when using them in different locations and situations. In the European context, adaptation may be more relevant than formulation.

Among guideline developers and policy makers there are always concerns about compliance. Better compliance is associated with good quality of evidence in support of recommendations and with the type of health problem. When recommendations are compatible with existing values in an organisation and require few organisational changes, they are more likely to be accepted. Similarly, if they are simple and do not require new skills, they are implemented more readily.

There are several implementation aspects:

- Dissemination issues: you cannot implement something you do not know about. All possible means must be used to reach the target groups: hard and electronic copies, publications and websites, full versions and summaries.
- Timing: a guideline is almost always out of date as soon as it is published! Revisions of guidelines are needed, and review periods may be shortened if necessary. Revised guidelines should clearly indicate all updated sections.
- Individual refusal: Some professionals may reject guidelines; people will not implement guidelines they do not agree with. Therefore the group that develops guidelines should have the support of all relevant stakeholders and should be credible. If guidelines are relevant and supported by management, then individuals will need to justify why they are not following the recommended practice.
- Financial issues: if implementing the recommendations is too costly, they will not be implemented. Affordability is a political issue, but resource implications in terms of people, facilities, training and timing should all be addressed in the guideline.
- Patient issues are important: people will not agree to treatments they do not want. In primary care, patient opinion is a more dominant factor than in hospital care.
- Legal, social or ethical issues: a guideline that is not context-specific is unlikely to be implemented.

Research on barriers to implementation of guidelines was only carried out for clinical guidelines, but it can be assumed that these findings are applicable to non-clinical guidelines as well.

Public health guidelines require an adjusted approach: the evidence base is different from the one commonly used in clinical guideline development, i.e. the approach is based on epidemiological and empirical evidence rather than clinical trials. Public health uses a population perspective rather than an individual one. Overcoming the barriers to implementation is critical for success. It is important to develop a clear strategy from the very beginning. Local, national and international collaboration is necessary to overcome barriers, but should always have an added value. The conditions for collaboration should be clear. The Guidelines International Network now has 89 member organisations in 38 countries, and a library of over 5 000 guidelines. The collaboration reduces the duplication of work and facilitates mutual support in guideline development. Information and training are provided through annual conferences, transnational project groups, training courses, and events. Within G-I-N, there are communities of practice, and international informal groups for exchange and collaboration.

Howard Needham, ECDC Scientific Liaison Officer, Scientific Advice Unit: The roles of EU and EDCC in guideline development

Clinical and public health guidelines guide decisions and establish criteria in specific areas of healthcare; they identify, summarise and evaluate the best evidence; they identify decision options and their outcomes (sometimes with algorithms) and standardise procedures. The aim of guidelines is to raise the quality of care and achieve the best balance between cost and clinical/public health outcomes.

In the EU, Member States are responsible for healthcare. But public health has an element of consumer protection, and domestic animal health is an EU responsibility. Many professional societies in Europe produce guidelines or recommendations. There are around 5 900 European guidelines (PubMed, July 2008), 390 of which are on infections.

The advantages of guideline development at the European level are increased efficiency, improved evidence base and increased equity. In some cases they can be supported by legislation (e.g. *Legionella* control). Some of the disadvantages of European guidelines are their inability to take local circumstances into account (epidemiology, health systems), language barriers, and (perceived) interference in local healthcare management.

According to ECDC's founding regulation, 'the Centre shall provide independent scientific opinions, expert advice, data and information.' But ECDC's Management Board decided in 2008 that 'ECDC should give guidance, not guidelines or recommendations'. ECDC's primary role is as a risk assessor, and not as a risk manager. In fact, ECDC is still refining its relationship with the public health constituency and defining its role in guideline development.

ECDC became operational in May 2005, and in autumn that year the highly pathogenic avian influenza A(H5N1) arrived in Europe. Therefore, ECDC immediately focused on guideline development for the control of this disease. Guidelines were quickly produced and with little consultation. Later, scientific panels were introduced in order to solicit expert advice from outside ECDC. Current ECDC advice procedures are consolidated, following established formats of evidence base, options and advice rather than prescriptive instructions. Occasionally, roadmaps are produced.

ECDC has to address future challenges. Can ECDC, together with its EU public health partners, continue to further define its role in guideline development in an EU context? Can ECDC develop standardised approaches and improve its tools to ensure the accuracy and consistency of its scientific advice? Can ECDC develop systems to verify and share EU-relevant guidelines?

ECDC could provide an EU guideline repository and quality assessment on guidelines. It could disseminate non-ECDC guidelines or could formulate dedicated ECDC guidelines. There is a need for a more standardised approach to ECDC scientific advice in order to improve consistency and accuracy. ECDC will produce standard operating procedures for the production of scientific advice; it will have an ECDC Expert Database (EED), and it will develop a system for grading the quality of evidence in order to control infectious diseases.

There is a clear need for dialogue with policy makers, with scientists and with public health practitioners, but the methods of consultation and communication still need refinement. Public health learned societies could play a role in the process by encouraging experts to support ECDC's work, e.g. by producing guidelines that add EU-value, and by sharing them with others. ECDC invites the societies to provide input into the debate about how ECDC should be involved in guideline development, production and dissemination.

Inge Gyssens, ESCMID: The role of European learned societies in public health guideline development

The purpose of guidelines is to improve quality, to support public health decisions and to diminish unwanted diversity of practice. Guidelines increase transparency (for the healthcare worker and the public). Within Europe there are huge differences in the acceptance of guidelines.

If ECDC initiates an EU public health guideline programme, it should follow the AGREE¹⁰ or ADAPTE¹¹ methodologies. Essential steps are the identification of health topics (scoping) and stakeholders. The learned societies could play a role in this.

When ECDC identifies health topics for guideline development, it could contact learned societies that have specialised knowledge in this area. Similarly, when ECDC identifies stakeholders, the learned societies could provide information. Many learned societies have study groups in specific areas (see ESCMID website).

Several pan-European societies are developing clinical and laboratory guidelines, which may be too narrow: collaboration between the societies with ECDC as catalyst may generate a multidisciplinary approach and may reduce contradictory recommendations. Guidelines should also be updated regularly. European learned societies could also play a role in the dissemination of guidelines, for example through publication in their journals or through their websites.

The learned societies could play a role in follow-up procedures and assess whether guidelines are used appropriately. The societies could investigate whether structures are in place that guarantee the application of guidelines or measure the compliance rate for guidelines. Through their networks, the learned societies could contribute to investigations into the effectiveness of guidelines on the health burden.

Implementing guidelines at the national or local levels will remain the biggest challenge.

¹⁰ See <http://www.agreecollaboration.org/>

¹¹ See <http://www.adapte.org/>

Annex 2: Agenda of the meeting

Tuesday, 2 December 2008

- 08:30 – 10:00 Registration and introduction
- 08:30 – 09:00 Registration
- 09:00 – 09:15 Opening: Zsuzsanna Jakab, Director, ECDC
- 09:15 – 09:20 Introductory remarks: Johan Giesecke, Head, Scientific Advice Unit (SAU), ECDC
- 09:20 – 9:40 The purpose of the Scientific Consultation Group: Jan Semenza, Section head Future Threats and Determinants, SAU, ECDC
- 09:40 – 13:00 Session 1: Collaboration in research of infectious diseases. Chair: Johan Giesecke
- 09:40 – 10:10 Overview of research in infectious diseases in Europe: Koos van der Velden, Radboud University, Nijmegen
- 10:10 – 10:40 Coffee break
- 10:40 – 11:15 DG Research FP7 research priorities in infectious diseases: Cornelius Schmaltz, DG Research, European Union
- 11:15 – 12:00 Collaboration in European research, panel discussion speakers and plenary discussion: Martin Rusnak, Trnava University, Slovak Republic
- 12:00 – 12:10 Introduction to break-away session live-blog for collaboration in research: Jaap Koot, Public Health Consultants, the Netherlands
- 12:10 – 13:00 Live-blog in small groups
- 13:00 – 14:00 Lunch
- 14:00 – 17:30 Session 2: Long-term perspective on priority setting in research of infectious diseases. Chair: Jan Semenza, ECDC
- 14:00 – 14:20 Future threats to public health in Europe: Jonathan Suk, ECDC
- 14:20 – 14:35 Criteria for priority setting in research: Jaap Koot and Martin Rusnak
- 14:35 – 14:45 The White Paper of European Medical Research Councils
- 14:45 – 14:50 Introduction to group assignment: Martin Rusnak
- 14:50 – 16:00 Group assignment: Future of priority setting
 - Group A: The process of setting priorities in research. Chair: Martin Rusnak
 - Group B: Priority topics in research. Chair: Koos van der Velden
- 15:00 – 15:15 Coffee break (during group assignments)
- 16:00 – 17:15 Plenary presentations on group work and discussion, formulation of recommendations. Chair: Koos van der Velden
- 17:15 – 17:30 Wrap up: Jan Semenza, ECDC

Wednesday, 3 December 2008

- 09:00 – 12:00 Session 3: Development of guidelines and standards. Chair: Koos van der Velden
- 09:00 – 09:45 Guidelines standards and evidence: Niek Klazinga, OECD
- 09:45 – 10:15 Barriers for the implementation of guidelines: Sara Twaddle, GIN, SIGN
- 10:15 – 10:45 Coffee break
- 10:45 – 11:10 ECDC's role in guideline development: Howard Needham, ECDC
- 11:10 – 11:30 The role of European learned societies in guideline development: Inge Gyssens, ESCMID scientific committee
- 11:30 – 12:00 Plenary discussion: Lessons learned. Chair: Koos van der Velden
- 12:00 – 13:00 Lunch
- 13:00 – 14:00 Group session: Recommendations for further actions — European support to guideline development in Member States
 - Group A: European institutions. Chair: Howard Needham
 - Group B: European learned societies. Chair: Inge Gyssens
- 14:00 – 15:00 Plenary discussion and formulation of recommendations. Chair: Koos van der Velden
- 15:00 – 15:30 Coffee break
- 15:30 – 16:30 Final remarks
- 15:30 – 16:15 The way forward for the Scientific Consultation Group (discussion). Chair: Jan Semenza, ECDC
- 16:15 – 16:30 Closing remarks: Johan Giesecke, ECDC

Annex 3: List of participants

Name and organisation

Bengtsson, Mats, European Federation for Immunogenetics (EFI)
 Blasi, Francesco, European Respiratory Society(ERS)
 Boeree, Martin, Federation of European Societies for Tropical Medicine and International Health (FESTMIH)
 Brand, Angela, European Centre for Public Health Genomics (ECPHG)
 Bruschi, Fabrizio, European Federation of Parasitologists (EFP)
 Charpak, Yves, Pasteur Institute
 Girardi, Enrico, European Network of Infectious Diseases (EUNID)
 Granström, Marta, European Society for Emerging Infections (ESEI)
 Gyssens, Inge C., European Society of Clinical Microbiology and Infectious Diseases (ESCMID)
 Hofdijk, Jacob, European Federation for Medical Informatics (EFMI)
 Jelinek, Thomas, European Network on Imported Infectious Disease Surveillance (TropNetEurop)
 Kallings, Ingegerd, European BioSafety Association (EBSA)
 Kennedy, Seamus, The European Society of Veterinary Pathology (ESVP)
 Khelef, Nadia, Pasteur Institute
 Kirk, Ole, European AIDS Clinical Society (EACS)
 Klazinga, Niek, Academisch Medisch Centrum AMC/UvA
 Koopmans, Marion, European Society for Clinical Virology (ESCV)
 Koot, Jaap, Public Health Consultants in Action
 Kučinskas, Vaidutis, European Society of Human Genetics (ESHG)
 Mackenzie, Fiona, International Society of Chemotherapy (ISC)
 Messmer, Konrad, European Institute of Health(EIH) of the European Academy of Sciences and Arts
 Nagy, Elisabeth, European Society of Clinical Microbiology and Infectious Diseases (ESCMID)
 Novelli, Andrea, Federation of European Societies for Chemotherapy and for Infections (FESCI)
 Odysseos, Andreani D., European Federation of Biotechnology (EFB)
 Ondrusova, Adriana, Trnava University
 Pekkarini, Päivi, European Association for Health Information and Libraries (EAHIL)
 Piffaretti, Jean-Claude, Federation of European Microbiological Societies (FEMS)
 Pöder, Airi, International Union against Sexually Transmitted Infections (IUSTI)
 Portincasa, Piero, European Society for Clinical Investigation (ESCI)
 Röllinghoff, Martin, Medical Sciences Unit (EMRC) of the European Science Foundation (ESF)
 Rosenmöller, Magdalene, European Health Management Association (EHMA)
 Rusnak, Martin, Trnava University, Slovak Republic
 Schmaltz, Cornelius, Emerging Infectious Diseases European Commission
 Silva, Ivana, Pharmaceutical Group of the European Union (PGEU)
 Thomas, Sue, European Association for Health Information and Libraries (EAHIL)
 Twaddle, Sara, Guidelines International Network (G-I-N)
 van den Neucker, Ingrid M., European CanCer Organisation (ECCO)
 van der Velden, Koos, Radbound Universiteit Nijmegen
 van Essen, Ted, The European Scientific Working group on Influenza (ESWI)
 van Leeuwen, Menno, Standing Committee of European Doctors (CPME)
 Villari, Paolo, Federation of European Academies of Medicine(FEAM)
 von Sonnenburg, Frank, International Society of Travel Medicine (ISTM)
 Williams, David, European Society for Emergency Medicine (EuSEM)

Giesecke, Johan, ECDC, SAU
 Needham, Howard, ECDC, SAU
 Semenza, Jan, ECDC, SAU
 Suk, Jonathan, ECDC, SAU

Annex 4. Pan-European learned societies

| Name of organisation/association | Website |
|---|---|
| European Society for Clinical Virology (ESCV) | http://www.escv.org/ |
| European Centre for Public Health Genomics (ECPHG) | http://www.phgen.nrw.de/typo3/index.php |
| International Union against Sexually Transmitted Infections (IUSTI) | http://www.iusti.org/ |
| European Federation for Immunogenetics (EFI) | http://www.efiweb.eu/ |
| European AIDS Clinical Society (EACS) | http://www.eacs.eu/ |
| European Scientific Working group on Influenza (ESWI) | http://www.eswi.org/ |
| European Medical Research Councils (EMRC) | http://www.esf.org/research-areas/medical-sciences.html |
| Pharmaceutical Group of the European Union (PGEN) | http://www.pgeu.org/ |
| European Society for Emerging Infections (ESEI) | http://www.esei2007.com/ |
| Federation of European Societies Tropical Medicine and International Health (FESTMIH) | http://www.festmih.eu/name/Home.html |
| European Cancer Organisation (ECCO) | http://www.ecco-org.eu/ |
| European Society of Veterinary Pathology (ESVP) | http://www.esvp.eu/ |
| European Society of Human Genetics (ESHG) | http://www.eshg.org/ |
| Standing Committee of European Doctors (CPME) | http://www.cpme.be/ |
| European Federation of Biotechnology (EFB) | http://www.efb-central.org/ |
| European Federation of Parasitologists (EFP) | http://monsite.orange.fr/europfedpar/ |
| European Association for Health Information and Libraries (EAHIL) | http://www.eahil.net/ |
| European Society of Clinical Microbiology and Infectious Diseases (ESCMID) | http://www.escmid.org/ |
| European Institute of Health (EIH) | http://www.eih-eu.org/ |
| European Network of Infectious Diseases (EUNID) | http://www.eunid.eu/ |
| European Network on Imported Infectious Diseases Surveillance (TropNetEurop) | http://www.tropnet.net/ |
| European Society for Emergency Medicine (EUSEM) | http://www.eusem.org/ |
| Federation of European Academies of Medicine (FEAM) | http://www.feam.eu.com/ |
| European Federation of Medical Informatics (EFMI) | http://www.helmholtz-muenchen.de/ibmi/efmi/ |
| European Health Management Organisation (EHMA) | http://www.ehma.org/ |
| European Respiratory Society (ERS) | http://dev.ersnet.org/ |
| Federation of European Societies for Chemotherapy and infection (FESCI) | http://www.fesci.net/ |
| International Society of Chemotherapy-Infection and Cancer (ISC-ic) | http://www.ischemo.org/ |
| European Society for Clinical Investigation (ESCI) | http://www.esci.eu.com/ |
| Federation of European Microbiology Societies (FEMS) | http://www.fems-microbiology.org/website/nl/default.asp |
| European BioSafety Association (EBSA) | http://www.ebsaweb.eu/ |