

Brussels, 4 June 2019

COST 035/19

DECISION

Subject: **Memorandum of Understanding for the implementation of the COST Action “European Burden of Disease Network” (burden-eu) CA18218**

The COST Member Countries and/or the COST Cooperating State will find attached the Memorandum of Understanding for the COST Action European Burden of Disease Network approved by the Committee of Senior Officials through written procedure on 4 June 2019.



MEMORANDUM OF UNDERSTANDING

For the implementation of a COST Action designated as

COST Action CA18218 EUROPEAN BURDEN OF DISEASE NETWORK (burden-eu)

The COST Member Countries and/or the COST Cooperating State, accepting the present Memorandum of Understanding (MoU) wish to undertake joint activities of mutual interest and declare their common intention to participate in the COST Action (the Action), referred to above and described in the Technical Annex of this MoU.

The Action will be carried out in accordance with the set of COST Implementation Rules approved by the Committee of Senior Officials (CSO), or any new document amending or replacing them:

- a. "Rules for Participation in and Implementation of COST Activities" (COST 132/14 REV2);
- b. "COST Action Proposal Submission, Evaluation, Selection and Approval" (COST 133/14 REV);
- c. "COST Action Management, Monitoring and Final Assessment" (COST 134/14 REV2);
- d. "COST International Cooperation and Specific Organisations Participation" (COST 135/14 REV).

The main aim and objective of the Action is to integrate and strengthen capacity in burden of disease assessment across Europe and beyond. This will be achieved through the specific objectives detailed in the Technical Annex.

The economic dimension of the activities carried out under the Action has been estimated, on the basis of information available during the planning of the Action, at EUR 124 million in 2018.

The MoU will enter into force once at least seven (7) COST Member Countries and/or COST Cooperating State have accepted it, and the corresponding Management Committee Members have been appointed, as described in the CSO Decision COST 134/14 REV2.

The COST Action will start from the date of the first Management Committee meeting and shall be implemented for a period of four (4) years, unless an extension is approved by the CSO following the procedure described in the CSO Decision COST 134/14 REV2.

OVERVIEW

Summary

What are the most relevant diseases in a country? Which risk factors are the strongest contributors to disease and death? How is the impact of different diseases evolving over time, and how does it compare between countries and within subnational units? As the need for prioritising the use of available resources constantly increases, a timely, sound and comprehensive answer to these fundamental questions is more than ever needed to inform public health decision making. Driven by the impact of the Global Burden of Disease study, several researchers and national and international health institutes have adopted the burden of disease approach to address these questions.

The complexity of the burden of disease approach however resulted in major disparities in research capacity across Europe. The burden-eu COST Action will address current challenges by 1) stimulating interaction between existing efforts, 2) supporting technical capacity building at country level, 3) providing a platform to support methodological advances, and 4) addressing the need for an actionable understanding of the process underlying knowledge translation.

The Action will have an interwoven structure of 3 vertical and 2 horizontal pillars. The vertical pillars focus on specific burden of disease applications – i.e., non-communicable diseases and injuries (WG1), communicable diseases (WG2), and risk factors (WG3). The horizontal pillars focus on cross-cutting and holistic activities – i.e., burden of disease methodology (WG4) and knowledge translation (WG5). While the vertical pillars reflect the current fragmented nature of the burden of disease universe, the horizontal pillars provide the much needed bridge between these different worlds.

<p>Areas of Expertise Relevant for the Action</p> <ul style="list-style-type: none"> ● Health Sciences: Public and environmental health ● Health Sciences: Epidemiology ● Health Sciences: Infectious diseases ● Health Sciences: Environment and health risks including radiation ● Clinical medicine: Non-communicable diseases 	<p>Keywords</p> <ul style="list-style-type: none"> ● Burden of disease ● Public health ● Knowledge translation ● Population health monitoring ● Prioritisation
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Specific Objectives

To achieve the main objective described in this MoU, the following specific objectives shall be accomplished:

Research Coordination

- To bring together experts and expertise across different domains, transforming the currently scattered burden of disease landscape into one transnational team.
- To compare and harmonize methods and approaches for burden of disease assessment.
- To identify critical knowledge and data gaps, and set up studies for which international coordination is needed.
- To serve as an advocacy group for the burden of disease approach in Europe.

Capacity Building

- To build and increase capacity in burden of disease assessment across Europe. The Action will have an explicit focus on the involvement of specific target groups, including Early Career Investigators, the under-represented gender, and teams and countries with less capacity in the field of burden of disease.
- To serve as a technical platform where knowledge and expertise can be shared among established and emerging researchers.
- To promote an interdisciplinary approach that integrates knowledge translation in the classical burden of

disease framework.

1 S&T EXCELLENCE

1.1 SOUNDNESS OF THE CHALLENGE

1.1.1 DESCRIPTION OF THE STATE-OF-THE-ART

What are the most burdensome diseases in a country? Which risk factors are the strongest contributors to disease and death? How is the impact of different diseases evolving over time, and how does it compare between countries? How do subnational units or specific population groups within a country compare? As the need for prioritising the use of available resources constantly increases, a timely, sound and comprehensive answer to these fundamental questions is more than ever needed to inform public health decision making.

Current evidence-based public health policy, further supported by the strive for Health in All Policies (HiAP), requires coherent and comparable estimates of the burden of diseases, injuries and risk factors in a country. Furthermore, with ageing populations and the growing importance of non-fatal conditions, there is a need for comprehensive measures of population health, combining morbidity and mortality and taking account of health-related quality of life. Summary measures of population health such as the Disability-Adjusted Life Year (DALY) have therefore become key metrics for quantifying burden of disease. DALYs quantify the health gap between a life lived in perfect health and current health status, as the number of healthy life years lost due to illness (Years Lived with Disability, YLDs) and premature death (Years of Life Lost, YLLs) (Murray, 1994). The DALY metric is the core element of the burden of disease approach, which is a systematic and highly standardised scientific effort to quantify the comparative magnitude of health loss due to disease, injury, and risk factors by age, sex, and geography for specific points in time.

Today, the two key global advocates of the burden of disease approach are the World Health Organization (WHO) and the Institute for Health Metrics and Evaluation (IHME) at the University of Washington, USA. These institutions have been, and continue to be, instrumental in the establishment of the Global Burden of Disease (GBD) studies (Murray and Lopez, 2017). Today, the GBD study led by IHME generates annual updates of the burden of disease, injury, and risk factors, at global, regional, national, and increasingly, sub-national level (GBD 2017 DALYs and HALE Collaborators, 2018). Their internally consistent and globally comparable estimates of illness, deaths, and DALYs have therefore become a key input for population health monitoring at national and international levels.

Driven by the impact of the GBD study, several researchers and public health institutes took up the burden of disease approach and initiated burden of disease studies for specific causes and/or geographies. A recent mapping study of burden of disease initiatives within Europe identified a total of 198 studies published since 1997, including over 20 full national or sub-national burden of disease studies, performed in 10 European countries (O'Donovan et al., 2018). Furthermore, several EU agencies have adopted the burden of disease approach for quantifying the health impact of their causes of concern. For instance, the European Centre for Disease Prevention and Control (ECDC) launched the Burden of Communicable Diseases in Europe (BCoDE) project, which assessed the burden for 31 communicable and 6 healthcare-associated infectious disease in Europe (Cassini et al., 2016, 2018).

1.1.2 DESCRIPTION OF THE CHALLENGE (MAIN AIM)

The increasing prominence of the burden of disease approach comes at a cost. The burden of disease methodology is complex and highly data demanding, requiring a substantial capacity to apply, which has led to **major disparities** across researchers and nations in their capacity to perform themselves burden of disease studies, interpret the soundness of available burden of disease estimates produced by IHME and others, or advocate for the use of burden of disease metrics. Often, these disparities follow geographical boundaries. The mapping study mentioned above showed that over half of all burden of disease publications were set in the Netherlands, Spain and UK, while only 15% of all publications were set in COST Inclusiveness Target Countries.

Furthermore, there are different methodological choices that are made when performing burden of disease studies, which **hamper comparisons of burden of disease studies** and drawing conclusions across studies. This is further aggravated by the fact that different burden of disease initiatives have **remained scattered**, often following the delineations of the specific applications. There is for instance little interaction between burden of disease initiatives conducted by infectious disease epidemiologists and environmental health experts, even though several methodological issues transcend the boundaries of diseases and risk factors. Finally, many burden of disease researchers are struggling to find optimal ways to **translate their findings** and communicate them to the relevant decision makers and other stakeholders.

The **relevance and timeliness** of the identified challenges is evident by the increasingly important role burden of disease plays in public health decision making, both at national and international levels. As more and more countries are implementing or using the burden of disease approach, there is an increasing need for equitable capacity building on the one hand (including an improved understanding of the complex methods behind IHME and other burden estimates), and harmonisation of methods on the other hand. Furthermore, current evolutions in public health, including big data and precision public health, call for a technical platform to foster the integration of these concepts in the burden of disease approach. Finally, to truly support decision making, there is an urgent need to better understand how knowledge translation can be integrated within the burden of disease approach.

1.2 PROGRESS BEYOND THE STATE-OF-THE-ART

1.2.1 APPROACH TO THE CHALLENGE AND PROGRESS BEYOND THE STATE-OF-THE-ART

The Challenges described in Section 1.1.2 are best addressed through networking. The **burden-eu** COST Action will bring together, for the first time, burden of disease experts working in a variety of domains, and provide a unique platform for developing knowledge and capacity across Europe. The Action will allow progressing beyond the current situation in four distinct ways:

1. The Action will address the need for increased interaction between existing efforts. The Action will serve as platform to bring together expertise across different domains and professional backgrounds, ranging from experts in infectious diseases, non-communicable diseases, injuries and risk factors, to experts in more comprehensive national, regional and global burden of disease studies. By bringing together this expertise, it will become possible to move beyond the currently scattered burden of disease landscape. By comparing different existing burden of disease initiatives, methodological differences will become evident and the road will be paved towards improvements and harmonisation of methods and approaches.

2. The Action will address the need for technical capacity building at country level. Today, there are important disparities in capacity to perform and interpret burden of disease studies across researchers and countries. The Action will serve as a capacity building platform for those interested in getting familiar with the burden of disease approach or further increasing their skills to interpret and perform burden of disease studies.

3. The Action will address the need for a platform to support methodological advances. Burden of disease methodology is complex, highly data demanding, and subject to constant evolution, further driven by the rapidly evolving domain of public health. Many of these methodological challenges transcend the boundaries of diseases and risk factors, and connect to domains such as economics, mathematics, and statistics. The Action will therefore be in a unique position to discuss and advance burden of disease methodology, and to work towards a joint burden of disease research agenda,

including an identification of common key challenges and knowledge and data gaps. The Action will provide an ideal context for leveraging national funding to support these research activities.

4. The Action will address the need for an actionable understanding of the process underlying knowledge translation. While the final goal of burden of disease studies is to inform decision making, e.g., by defining priorities or unmet health needs, burden of disease experts struggle to find the best ways to achieve this. In collaboration with experts in knowledge translation, the Action will make important and much needed steps towards effective translation of evidence into practice.

1.2.2 OBJECTIVES

1.2.2.1 Research Coordination Objectives

One of the key purposes of the burden-eu COST Action is to bring together experts and expertise across different domains. Through various specific research coordination objectives, the Action will allow transforming the currently scattered burden of disease landscape into one transnational team.

By comparing different existing burden of disease initiatives, including the IHME GBD study, methodological differences will become evident and the road will be paved towards **harmonisation of methods and approaches**. This will be achieved through the following activities:

- Development of a continuously updated database of burden of disease studies in Europe
- Development of reporting guidelines for burden of disease studies, and DALY calculations in particular
- Development of an updated roadmap for national burden of disease studies
- Development of standardised and open access training material, including massive open online courses (MOOCs)

By bringing together burden of disease experts from different countries, the Action will allow identifying critical knowledge and data gaps, and setting up **studies for which international coordination is needed**. Specific examples may include the following:

- Interpretation of the GBD results for Europe and their use for policy development and monitoring
- Implementation and evaluation of regression-based approaches for redistributing ill-defined deaths to relevant and plausible target causes, leveraging multinational cause-of-death data
- Providing guidelines for the selection and mapping of health state disability weights
- Providing guidelines for the definition and selection of severity distributions
- Facilitating and coordinating efforts to produce subnational burden of disease results
- Preparation of projects and studies, leveraging available national funding, which address identified common key challenges, bottle necks, knowledge and data gaps, and needs

Finally, the Action will serve as an **advocacy group** for the burden of disease approach in Europe, creating awareness and acceptance of burden of disease among all relevant stakeholders, including public health decision makers, patient organisations, and industry. The website and social media accounts of the Action will further provide a unique portal to the dissemination of research results to the general public and stakeholders. Further dedicated activities will involve active presence at national and international conferences and the organisation of workshops with the concerned stakeholders.

1.2.2.2 Capacity-building Objectives

Capacity building will be at the heart of this Action. To address the current disparities in burden of disease research capacity, the Action will build strongly on the COST mechanisms to **build and increase capacity** across Europe:

- Researchers will be encouraged to visit one of the countries where burden of disease has been established, to work on a specific burden of disease calculation or to pave the way to a national burden of disease study; interaction with international partners will create further opportunities for sharing knowledge and expertise.
- Training schools will be organised in Inclusiveness Target Countries, using the standardised training material mentioned above
- Regular meetings and workshops will allow further exchange of knowledge and expertise and provide valuable contact moments to form new partnerships and collaborations.

- Open access, online training material; to have an even wider reach and extend the impact beyond the duration of the Action

The Action will furthermore serve as a **technical platform** where knowledge and expertise can be shared among established and emerging researchers. Collaboratively, the technical platform will provide unique opportunities for developing a joint research agenda in the domain of burden of disease, for fostering methodological developments, and for developing new collaborative research projects.

The Action will have an explicit focus on the **integration of knowledge translation** in the burden of disease approach. The Action will promote an interdisciplinary approach that integrates this discipline in the classical burden of disease framework, to support breakthroughs that cannot be achieved in isolation. Specific activities will include the following:

- Explicit integration of knowledge translation in the Action's structure (see 4.1.1)
- Organisation of workshops with experts in the field of knowledge translation
- Compilation of best practices in knowledge translation in the context of burden of disease studies, including identification of obstacles for knowledge translation
- Development of a roadmap for knowledge translation of burden of disease estimates

The Action will have an explicit focus on the **involvement of specific target groups**, including Early Career Investigators (ECI), the under-represented gender, and teams and countries with less capacity in the field of burden of disease. Specifically, leadership positions within the Action's structure will be assigned in accordance to these criteria (see 4.1.1). As mentioned before, special attention will be given to the active inclusion of researchers from ITCs in training opportunities.

One of the key overall objectives will be to facilitate burden of disease activities in all partner countries, and in particular in those countries with currently little experience in burden of disease. The database of burden of disease studies in Europe, introduced in Section 1.2.2.1, will provide the necessary means to measure the level of achievement of this objective.

2 NETWORKING EXCELLENCE

2.1 ADDED VALUE OF NETWORKING IN S&T EXCELLENCE

2.1.1 ADDED VALUE IN RELATION TO EXISTING EFFORTS AT EUROPEAN AND/OR INTERNATIONAL LEVEL

In recent years, the European Commission has supported various projects to maintain and further develop health information systems (Bogaert et al., 2018). The BRIDGE Health project has taken stock of health information experience and expertise around Europe. The InfAct Joint Action aims to level out inequalities in health information and develop a structure to maintain health information capacity and governance sustainable in the future. Eurostat has a number of significant health information activities, including the work on the European Core Health Indicators (ECHI) (Fehr et al., 2018) and on diagnosis-based morbidity statistics. Since burden of disease assessments require high-quality health information, these projects provide the foundation on which the burden-eu COST Action can build. Furthermore, the knowledge translation activities of the Action may build on the insights and expertise of the European Observatory on Health Systems and Policies and the Evidence-informed Policy Network (EVIPNet). In return, the COST Action will provide most relevant feedback on essential knowledge, information, and data gaps to all the above and also the following projects and organisations.

In 2016, the WHO European Regional Office (WHO-EURO) established a European Burden of Disease Network (EBoDN) to bring together researchers from public health institutes and academia with an interest in national burden of disease studies (Stein and Newton, 2017). A key purpose of the EBoDN is to advise WHO on all technical and strategic matters relating to burden of disease. Compared to this network, the Action will have a broader scope and membership, and will be open to researchers from public health institutes, academia, and private organisations. Furthermore, whereas the WHO-EURO network mainly aims to provide strategic guidance, the Action will provide a much demanded technical platform for the exchange of knowledge and expertise.

Other existing efforts include the burden of disease activities that have been performed at the European level. Indeed, several European agencies have performed burden of disease studies in specific domains, e.g., the European Center for Disease Prevention and Control (ECDC; communicable

diseases), the European Environment Agency (EEA; air pollution), and the European Association for Injury Prevention (EuroSafe; injuries). The Action will provide a unique and necessary platform to bring these projects together and to establish links with European researchers and public health institutes. This will allow, amongst others, exploring methodological differences, improving and harmonising methods, and disseminating knowledge and expertise from the specific projects to a wider audience.

Finally, a key international effort is the Global Burden of Disease (GBD) study performed and managed by the Institute for Health Metrics and Evaluation (IHME) at the University of Washington, Seattle, USA. Increasingly, the GBD study builds on the engagement of country representatives, who can become involved in the endeavour as GBD collaborators. The Action will actively reach out to IHME to support exchange of technical expertise and to share knowledge and expertise among European researchers who are (interested in) working together with IHME to produce best available estimates for their country.. Indeed, as the GBD study is gaining prominence at multiple levels, European researchers will benefit from a better understanding of the methods and results and of the ways in which they can contribute to validation and improvement of the GBD estimates.

2.2 ADDED VALUE OF NETWORKING IN IMPACT

2.2.1 SECURING THE CRITICAL MASS AND EXPERTISE

The current network of proposers consists of 31 countries, including 20 ITCs, and one international organisation (the European Observatory on Health Systems and Policies). The network of proposers was designed to include **all components needed to achieve the goals of the Action**, and is comprised of researchers from academia, public health institutes and private organisations. As burden of disease is by definition a multidisciplinary domain, the network includes a wide variety of specialities, including epidemiologists, public, environmental and occupational health experts, clinicians, biostatisticians, demographers, and sociologists. The proposers further combine a wide range of expertise on burden of disease, ranging from methods to specific applications and national burden of disease studies, as well as knowledge translation . At the same time, the current network comprises individuals who are at the early stages of developing capacity in the burden of disease approach and wish to gain further experience.

A variety of avenues will be pursued to **continue enlarging the critical mass and expertise** throughout the Action's lifetime. First, burden of disease researches in Europe will be actively reached out to. These experts will include GBD collaborators and other experts identified through available mapping studies, as well as through the development of the database of burden of disease studies in Europe. Second, individuals and public health institutes wishing to gain further experience in the burden of disease approach, will be reached out through the aforementioned WHO-EURO EBoDN and InfAct platforms, as well as through the more general networks of the European Public Health Association (EUPHA), the International Association of Public Health Institutes (IANPHI), and the European Health Forum Gastein (which includes a specific focus on young health professionals). Enlargement of the network, with both experienced and interested partners, will be a key focus throughout the course of the Action.

Finally, the Action will also actively reach out to the aforementioned European and International organisations involved in burden of disease activities. The European Observatory on Health Systems and Policies has formalized its support, and will play an active role in the knowledge translation activities of the Action. Furthermore, the Institute for Health Metrics and evaluation (IHME), the European Centre for Disease Prevention and Control (ECDC) and the European Environment Agency (EEA) have been contacted to be involved in this Action and have expressed their interest in the objectives of the Action. If the application is successful, IHME, ECDC and EEA will be invited to participate in the COST Action. Legal and organisational constraints however restrict these agencies from acting as secondary proposer to the Action. It should also be noted that the current network of proposers has already secured relevant levels of experience and expertise in European and global burden of disease studies, and that we will continue reaching out to (European and international) researchers with expertise and involvement in global and regional burden of disease studies.

2.2.2 INVOLVEMENT OF STAKEHOLDERS

The key stakeholders for the Action's role as a **technical platform**, are academia, public health institutes, and international organisations involved in burden of disease studies. The involvement of these stakeholders has been detailed in the previous section.

The Action will also play a role as **advocacy group** for the burden of disease approach in Europe. It will create awareness and a better understanding of the benefits of the burden of disease approach and thereby foster acceptance of the approach among all relevant stakeholders. Public health decision makers are a key target group, as they are the ones who decide whether to integrate burden of disease estimates in their prioritisation and decision making processes or not. Patient organisations typically focus on a specific disease, and require objective information on the clinical impact and relative importance of their disease to support case-making. Science and industry benefit from burden of disease estimates as they identify unmet health needs, which are possible targets for research and development. Finally, the general public has the right, and increasingly has the demand, to be informed on the relative importance of different diseases and risk factors that may affect them.

The website and social media accounts of the Action will provide a **unique portal** to the dissemination of research results to the general public and stakeholders. In addition to this passive dissemination of information and results, **dedicated activities** will be set up, including active presence at national and international conferences and the organisation of workshops with the concerned stakeholders. The latter will be of particular importance for supporting the work on knowledge translation. Indeed, creating awareness and understanding of burden of disease estimates requires close interaction with the stakeholders. These workshops will also allow us to learn from the stakeholders on what they conceive to be the most appropriate and effective way of transferring knowledge.

2.2.3 MUTUAL BENEFITS OF THE INVOLVEMENT OF SECONDARY PROPOSERS FROM NEAR NEIGHBOUR OR INTERNATIONAL PARTNER COUNTRIES OR INTERNATIONAL ORGANISATIONS

The main focus has been on developing a network of secondary proposers among the COST members. In the meantime, we have extended our invitations to various non-COST members. The inclusion of near neighbour countries will allow leveraging current collaborations and funding opportunities. The inclusion of International Partner Countries will allow bringing in additional expertise on burden of disease. Finally, the inclusion of European organisations that have been involved in burden of disease will allow harmonisation and bridging the gap between these organisations and European researchers.

As mentioned above, the European Observatory on Health Systems and Policies has formalized its support to this Action. The Observatory supports and promotes evidence-based health policy-making through comprehensive and rigorous analysis of the dynamics of health-care systems in Europe. It engages directly with policy-makers and experts, and works in partnership with research centres, governments and international organizations to analyse health systems and policy trends. The expertise of the Observatory on knowledge translation will be a crucial asset for the Action and will allow promoting transdisciplinarity and moving beyond the classical burden of disease networks.

3 IMPACT

3.1 IMPACT TO SCIENCE, SOCIETY AND COMPETITIVENESS, AND POTENTIAL FOR INNOVATION/BREAK-THROUGHS

3.1.1 SCIENTIFIC, TECHNOLOGICAL, AND/OR SOCIOECONOMIC IMPACTS (INCLUDING POTENTIAL INNOVATIONS AND/OR BREAKTHROUGHS)

In the **short-term**, the Action will have several relevant and realistic scientific and technological impacts:

- First of all, the Action will establish a much demanded network of experts in the field of burden of disease. The Action's website will serve as a portal to the network and its outputs, and will be maintained even after the Action will have come to an end.
- Second, throughout the course of the Action, relevant tools and training materials will be developed, including a checklist and roadmap for burden of disease studies, a roadmap for knowledge translation, and standardised training materials that will be disseminated within and beyond the network.
- Third, the Action will lead to new burden of disease studies through Short-Term Scientific Missions and other collaborations; these studies will lead to new insights in the burden of specific diseases or risk factors at subnational, national or regional level, and will lead to scientific publications and presentations.

- Fourth, the Action will foster methodological advances in the domain of burden of disease and will allow for cross-country studies.

In the **long-term**, the network and insights will support major impacts for science, society and competitiveness:

- Overall, the idea of burden of disease studies is to generate comparable and comprehensive estimates of the health impact of diseases, injuries and risk factors. By supporting capacity building in the domain of burden of disease, the Action will eventually lead to new and improved insights in the burden of disease across Europe. This will allow policy makers, industry, and other stakeholders, to identify unmet health needs and prioritise research, prevention and control accordingly. In the long run this should lead to improved population health in Europe. To support this interaction between research and decision making, an explicit focus will be laid on knowledge translation.
- The different tools developed by the Action will lead to a further harmonisation of burden of disease studies within Europe and beyond. This will lead to improved transparency of methods and results, and increased comparability between available and new burden estimates.
- The Action will enable Europe to play an active role in the rapidly developing and growing field of burden of disease, which has emerged as an essential field in descriptive epidemiology and population health studies, and as such is also increasingly used to guide efforts in more analytical/clinical epidemiology, public health, and health systems research in general.
- While the scope of the current Action is limited to burden of disease, it may lay the foundation for future networks on related domains, such as more clinical and analytical epidemiology, health impact and health technology assessments, or cost of disease, or with regard to the six building blocks of the health systems (e.g. service delivery or health financing).

3.2 MEASURES TO MAXIMISE IMPACT

3.2.1 KNOWLEDGE CREATION, TRANSFER OF KNOWLEDGE AND CAREER DEVELOPMENT

Knowledge creation, transfer of knowledge and career development will be at the heart of the Action:

- First of all, the network places an explicit focus on the inclusion of Early Career Investigators (ECI), and teams and countries with less capacity in the field of burden of disease, particularly those originating from Inclusiveness Target Countries (ITCs). The current composition already guarantees an appropriate mix of experienced researchers and those wishing to gain further experience and expertise. We will continue expanding our network to ensure maximum coverage and inclusion across Europe.
- The Action will actively build on the COST mechanisms to support capacity building across Europe. Training schools and workshops will preferably be held in ITCs to maximise participation rates, and Short-Term Scientific Missions that will strengthen capacity among ECIs and ITC partners will be given priority over exchanges between experienced partners.

3.2.2 PLAN FOR DISSEMINATION AND/OR EXPLOITATION AND DIALOGUE WITH THE GENERAL PUBLIC OR POLICY

The dissemination and communication plan of the Action will be developed in line with the Guidelines for the communication, dissemination and exploitation of COST Action results and outcomes. The Action's dissemination and communication strategy will be supervised by the Action's Communication Manager (a member of the Management Committee, MC). The Action and its working groups will have a consistent graphical identity (logo, font, etc.), used across activities. A state-of-the-art website will serve as the major dissemination hub:

- General information on objectives and Working Groups (WGs);
- Informing about news and events;
- Database of burden of disease studies;
- Hosting of tools and training materials; and
- Central contact point for involved burden of disease experts.

Specific dissemination activities for the scientific community will include:

- Establish and maintain social media accounts (e.g., Twitter, LinkedIn); this will mainly be a responsibility of the Action's Communication Manager
- Send regular announcements regarding its activities (conferences, workshops, training schools, publications, reports) to international mailing lists, newsletters and social media platforms
- Participate in international workshops and conferences (hosted by related communities) and present the Action's activities and results; this will mainly be a responsibility of the Action's core group
- Organise two major international conferences at the end of the 2nd and 4th year of the Action
- Organise workshops throughout the Action's operation
- Produce peer-reviewed papers (e.g., concept papers and systematic reviews) and/or special journal issues (e.g., meeting proceedings, research papers of COST partners)

These communication channels and tools serve to share and promote the Action's activities and results with the scientific community and beyond, and will contribute to the overall visibility of COST.

In addition to the scientific community, dialogue with policy, industry, patient organisations and other possible end users of burden of disease estimates will be a key objective of the Action. Specifically, the Working Group on knowledge translation will explore and examine what the best mechanisms are to translate information and knowledge resulting from burden of disease studies to the concerned stakeholders. By promoting transdisciplinarity and moving beyond the classical burden of disease networks, the Action will provide more effective answers to the key societal questions regarding the health impact of diseases and risk factors. Specific mechanisms may include the following:

- Outreach to decision makers following the Health in All Policies approach.
- Elaboration of policy briefs, i.e., concise summaries of particular studies and key messages.
- Active interaction between researchers, knowledge brokers, and end users, e.g. through organisation and/or participation in interactive workshops, discussion platforms, and roundtables.

Interaction with the general public will serve a direct purpose of informing about the general health status of the population and the most important diseases and risk factors; it will also serve an important indirect purpose as a mechanism to inform and influence decision makers. The interaction with the general public will happen through press statements, media appearances, and other mechanisms (e.g., social media) that will be developed by the Working Group on knowledge translation.

Last but not least, bids and proposals for dissemination efforts at national and local levels of network members will be supported. Thereby, the planned COST Action will also trigger a substantial multiplication effect at national and local levels.

4 IMPLEMENTATION

4.1 COHERENCE AND EFFECTIVENESS OF THE WORK PLAN

4.1.1 DESCRIPTION OF WORKING GROUPS, TASKS AND ACTIVITIES

General management structure

The management of the burden-eu COST Action will be carried out as per the regulations and procedures described in the COST Vademecum and with the aim of ensuring the Action objectives are achieved. As for all COST Actions, a **Management Committee (MC)** formed by up to two national experts of the signatory countries will be in charge of implementing, supervising and coordinating the activities of the Action, as well as promoting capacity building, managing the budget and disseminating the results. A **Chair and Vice Chair** of the Action will be elected at the first MC meeting and a **Grant Holder and Grant Holder Scientific Representative** will be selected. In the designation of these leadership positions, we will ensure a balance with respect to age, gender and geographical location. The current proposal for these positions involves an ECI as Chair, a female investigator from an ITC as Vice Chair, and a female ECI as Grant Holder Scientific Representative. The assigned Grant Holder Scientific Representative will assign persons to the positions of Grant Holder Legal Representative, Grant Holder Financial Representative and Grant Holder Manager (who will provide the necessary administrative support to organise, amongst others, the travel reimbursement requests). The MC will oversee the composition of various WGs, ensuring that the objectives can be achieved, accounting for the possible non-participation of some network members at certain key times as detailed in the

contingency plans. The deliverables and tasks are spread evenly over the 4 years and between different areas of expertise to avoid overloading network members. Each network member will be involved in at least two WGs, so their expected tasks within each will be clearly defined. The MC will ensure that funds are distributed accordingly in order to achieve the objectives, milestones and deliverables of the Action in a timely and efficient manner. It will also oversee the dissemination of results and the planning of network activities (e.g. meetings, conferences, workshops, training schools, and STSMs).

Each WG will be supervised by a **WG leader and co-leader**. The WG (co)leaders will ensure that activities run smoothly. These persons will be MC members who are able to commit the necessary time, but diversity will also be considered to ensure there is input from Early Career Investigators (ECI), COST Inclusiveness Target Countries (ITC), as well as a good gender balance. We will achieve this by striving for representation of ECI, ITC, and the minority gender within each leader/co-leader pair (e.g., a female ITC leader and an ECI co-leader). The leadership pair will be responsible for reporting on progress at meetings and helping prepare annual reports as well as identifying any targets that are unlikely to be met, so the MC can put contingency plans into action (e.g. identify other/new network members to complete tasks). WG leaders will need to communicate effectively with each other for smooth operation of the network. There will be a flow of knowledge exchange between WGs over the Action lifetime and it is expected that the WG leaders will be in regular contact, both formal and informal. They will also be expected to keep the network informed of relevant developments within their WG topic over the full 4 years of the network, not just when they are 'active'.

A **Communication Manager** (COMM) will be identified to support the Action's dissemination activities, including the management of the website and the Action's online/social media profile. Finally, a **Short-Term Scientific Mission Manager** (STSMM) will be responsible for managing the process of offer and demand of STSMs, and will be specifically tasked with encouraging participation from ITCs and ECIs; to support this process, the STSMM will be selected from one of the participating ITCs.

The Action's **Core Group**, consisting of the Chair, Vice Chair, Grant Holder representatives, WG leaders, COMM and STSMM, will coordinate the preliminary activities to be approved by the MC. MC meetings will be held at each of the main meetings, with additional communication on-line as necessary.

Working groups

The work that is foreseen within the burden-eu Action will be conducted within **five different working groups** (WG). Several methods will be used to achieve good communication within WGs and excellent integration between WGs. There will be frequent formal and informal contact moments both within and between the WGs. Four annual contact moments will be organised (face-to-face or via teleconference) between the members of the Core Group. Two face-to-face meetings will be held each year to share the progress and results of all WGs between the participants and to discuss the findings; these meetings will be combined with Management Committee meetings and COST conferences to increase participation and save budget.

The proposed organisation of the burden-eu COST Action WGs is an interwoven structure of **3 vertical pillars** and **2 horizontal pillars** (Fig 1). The 3 vertical pillars will focus on specific burden of disease applications – i.e., non-communicable diseases (NCDs) and injuries (WG1), communicable diseases (WG2), and risk factors (WG3). The 2 horizontal pillars will focus on cross-cutting activities – i.e., burden of disease methodology (WG4) and knowledge translation (WG5). The 3 vertical pillars reflect the current fragmented nature of the burden of disease universe, where applied researchers develop specific applications in their own domain of interest. The 2 horizontal pillars aim to bridge these different worlds by focussing on transversal, cross-cutting, and holistic themes. To support this process of interaction and interdisciplinarity, Action participants will be asked to identify with at least one vertical pillar and at least one horizontal pillar. During Action meetings, parallel sessions will be organised within the vertical pillars and within the horizontal pillars, but never across pillars (e.g., in the morning 3 parallel sessions for WG1–3, and in the afternoon 2 parallel sessions for WG4–5).

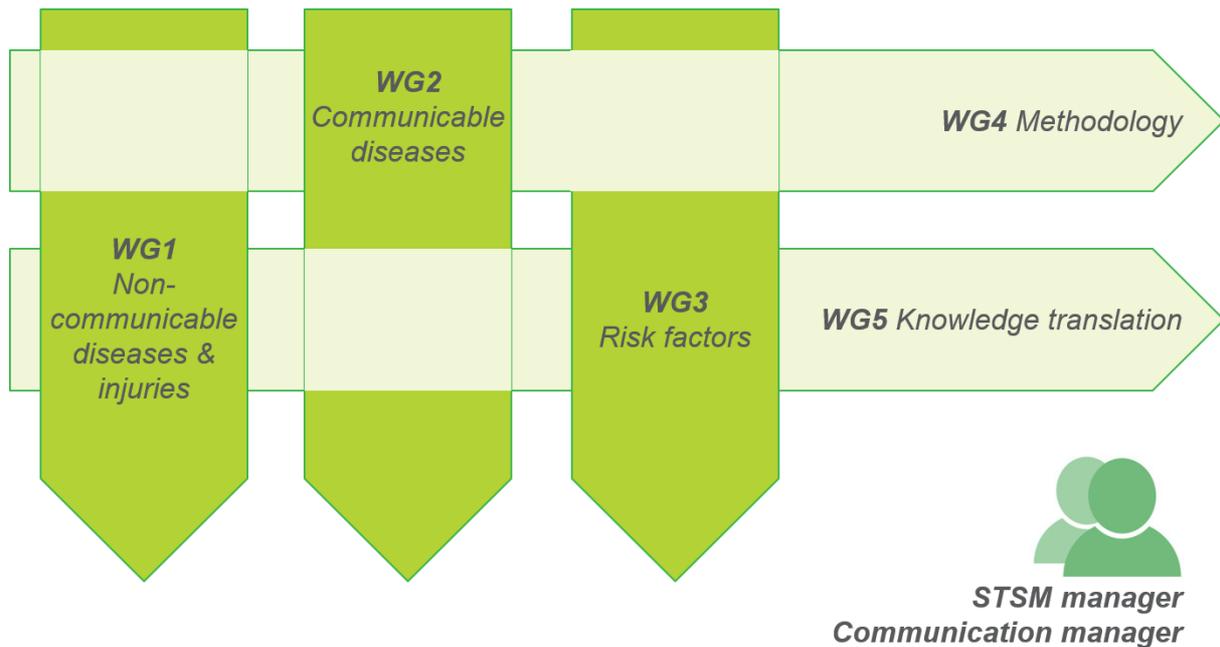


Figure 1. Operational structure of the burden-eu COST Action. WG: Working Group, NCD: Non-Communicable Disease, STSM: Short-Term Scientific Mission.

WG1: Non-communicable diseases and injuries

Non-communicable diseases (NCDs) and injuries account for the largest share of the disease burden in Europe. Specific challenges in the burden assessment of NCDs and injuries include the use of available health information for estimating the true prevalence of NCDs, and the definition of appropriate disease models and severity distributions for estimating years lived with disability.

Tasks & Activities

- **T-1.1** Mapping of burden of disease activities in the domain of NCDs and injuries
- **T-1.2** Involvement of burden of disease researchers in the domain of NCDs and injuries
- **T-1.3** Support burden of disease assessments in the domain of NCDs and injuries through initiating collaborative burden of disease studies among the partners
- **T-1.4** Foster methodological developments in burden of disease assessments in the domain of NCDs and injuries, including the identification of common essential key challenges, bottle necks, knowledge and data gaps, and needs
- **T-1.5** Provide feedback and expertise on methods and communication to support the activities of the transversal working groups

WG2: Communicable diseases

Communicable diseases include a broad range of diseases caused by sexually transmitted, vaccine-preventable, respiratory, foodborne, or zoonotic pathogens. Although the health impact of these diseases is generally lower than that of the non-communicable diseases, they require constant surveillance and control. Because of the wide range of communicable diseases, burden of disease studies have focussed on prioritising pathogens based on their current or potential health impact. In contemporary Europe, (re)emergence of eradicated or exotic pathogens, and insurgence of antimicrobial resistance, are further causes of increased vigilance.

Tasks & Activities

- **T-2.1** Mapping of burden of disease activities in the domain of communicable diseases
- **T-2.2** Involvement of burden of disease researchers in the domain of communicable diseases
- **T-2.3** Support burden of disease assessments in the domain of communicable diseases through initiating collaborative burden of disease studies among the partners
- **T-2.4** Foster methodological developments in burden of disease assessments in the domain of communicable diseases, including the identification of common essential key challenges, bottle necks, knowledge and data gaps, and needs

- **T-2.5** Provide feedback and expertise on methods and communication to support the activities of the transversal working groups

WG3: Risk factors

Estimating the disease burden associated with behavioural, metabolic, environmental, and occupational risk factors is of utmost importance for policy makers, because these factors have the potential to be modified by policy. Increasingly, burden of disease assessments consider social determinants of health in an attempt to quantify and monitor health inequalities. Improved information on the role of genetic and metabolomic factors (and the interactions between the genome and the “exposome”) is starting to add yet another layer of complexity to the contribution of risk factors to disease, disability, and death. Increasingly, a key challenge in assessing the burden of disease associated with risk factors, is therefore the disentangling of the interaction and interdependence between the different risk factors or in turn their combined effects on health. Conversely, as only about half of the global burden of disease can be attributed to known risk factors, further research is needed to identify additional important risk factors and to develop methods to quantify their impact even when knowledge is incomplete.

Tasks & Activities

- **T-3.1** Mapping of burden of disease activities in the domain of risk factors
- **T-3.2** Involvement of burden of disease researchers in the domain of risk factors
- **T-3.3** Support burden of disease assessments in the domain of risk factors through initiating collaborative burden of disease studies among the partners
- **T-3.4** Foster methodological developments in burden of disease assessments in the domain of risk factors, including the identification of common essential key challenges, bottle necks, knowledge and data gaps, and needs
- **T-3.5** Provide feedback and expertise on methods and communication to support the activities of the transversal working groups

WG4: Burden of disease methodology

Burden of disease methodology is complex and subject to constant evolution. Many of these methodological challenges transcend the boundaries of diseases and risk factors – e.g., methodological questions surrounding redistribution of ill-defined deaths, disability weights, comorbidity adjustments, and uncertainty quantification. This WG will also allow taking a more holistic and integrative view on burden of disease, as is the case in national burden of disease studies.

Tasks & Activities

- **T-4.1** Develop a burden of disease checklist
- **T-4.2** Develop an updated national burden of disease roadmap
- **T-4.3** Develop standardised burden of disease training material
- **T-4.4** Develop a joint burden of disease research agenda, including a summary of identified common essential key challenges, bottle necks, knowledge and data gaps, and needs

WG5: Knowledge translation

This WG will address the need for an actionable understanding of the process underlying knowledge translation. While the ultimate goal and benefit of burden of disease studies is to inform decision making, e.g., by defining priorities or unmet health needs, burden of disease experts have been struggling to find the best ways to achieve this. In collaboration with experts in knowledge translation, this WG will make important and much needed steps towards effective translation of evidence into practice.

Tasks & Activities

- **T-5.1** Compile good practices of knowledge translation, including the identification of obstacles for knowledge translation
- **T-5.2** Develop a knowledge translation roadmap for national burden of disease studies
- **T-5.3** Develop a knowledge translation toolbox

Core group

In addition to the dedicated tasks and activities of the Working Groups, the Core Group will be tasked with a set of key overarching tasks and activities.

Tasks & Activities

- **T-C.1** Development of the Action's website, including the database of burden of disease studies
- **T-C.2** Development and implementation of a communication and dissemination strategy (supervised by the Communication Manager)
- **T-C.3** Organisation of Short-Term Scientific Missions (supervised by the STSM manager)
- **T-C.4** Organisation of meetings and international conferences
- **T-C.5** Organisation of a mid-term review of the Action

4.1.2 DESCRIPTION OF DELIVERABLES AND TIMEFRAME

The deliverables follow the task & activities described above. The timeline of deliverables is presented in the GANTT diagram below. Over the course of the Action, we plan at least 7 Workshops, 5 Training Schools, and 16 Short-Term Scientific Missions. To ensure budgetary balance, these activities have been distributed evenly over the 4-years' lifetime of the Action.

WG1: Non-communicable diseases and injuries

- **D-1.1** Compilation of burden of disease studies in the domain of NCDs and injuries (continuous activity)
- **D-1.2** Identification and involvement of burden of disease researchers in the domain of NCDs and injuries (continuous activity)
- **D-1.3** At least 1 Workshop to support burden of disease assessments or methodological advances in the domain of NCDs and injuries
- **D-1.4** At least 1 burden of disease Training School in the domain of NCDs and injuries
- **D-1.5** At least 4 Short-Term Scientific Missions completed in the domain of NCDs and injuries
- **D-1.6** Scientific publications and presentations reporting on new burden of disease assessments in the domain of NCDs and injuries
- **D-1.7** Scientific publications and presentations reporting on common key challenges and knowledge and data gaps, and methodological advances in the domain of NCDs and injuries

WG2: Communicable diseases

- **D-2.1** Compilation of burden of disease studies in the domain of communicable diseases (continuous activity)
- **D-2.2** Identification and involvement of burden of disease researchers in the domain of communicable diseases (continuous activity)
- **D-2.3** At least 1 Workshop to support burden of disease assessments or methodological advances in the domain of communicable diseases
- **D-2.4** At least 1 burden of disease Training School in the domain of communicable diseases
- **D-2.5** At least 4 Short-Term Scientific Missions completed in the domain of communicable diseases
- **D-2.6** Scientific publications and presentations reporting on new burden of disease assessments in the domain of communicable diseases
- **D-2.7** Scientific publications and presentations reporting on common key challenges and knowledge and data gaps, and methodological advances in the domain of communicable diseases

WG3: Risk factors

- **D-3.1** Compilation of burden of disease studies in the domain of risk factors (continuous activity)
- **D-3.2** Identification and involvement of burden of disease researchers in the domain of risk factors (continuous activity)
- **D-3.3** At least 1 Workshop to support burden of disease assessments or methodological advances in the domain of risk factors
- **D-3.4** At least 1 burden of disease Training School in the domain of risk factors
- **D-3.5** At least 4 Short-Term Scientific Missions completed in the domain of risk factors
- **D-3.6** Scientific publications and presentations reporting on new burden of disease assessments in the domain of risk factors
- **D-3.7** Scientific publications and presentations reporting on common key challenges and knowledge and data gaps, and methodological advances in the domain of risk factors

WG4: Burden of disease methodology

- **D-4.1** At least 2 Workshops to support the activities of the Working Group
- **D-4.2** Burden of disease checklist
- **D-4.3** National burden of disease roadmap
- **D-4.4** Standardised burden of disease training material
- **D-4.5** At least 1 Training School on general burden of disease methodology
- **D-4.6** At least 2 Short-Term Scientific Missions completed in the domain of general burden of disease methodology
- **D-4.7** Joint burden of disease research agenda

WG5: Knowledge translation

- **D-5.1** Compilation of good practices of knowledge translation (continuous activity)
- **D-5.2** At least 2 Workshops to support the activities of the Working Group
- **D-5.3** Knowledge translation roadmap
- **D-5.4** Knowledge translation toolbox
- **D-5.5** At least 1 Training School on knowledge translation
- **D-5.6** At least 2 Short-Term Scientific Missions completed in the domain of knowledge translation

Core Group

- **D-C.1** Action website (+ continuous maintenance)
- **D-C.2** Burden of disease database (+ continuous maintenance)
- **D-C.3** Communication and promotional material (e.g., social media accounts, visual identity, flyers)
- **D-C.4** 8 joint Management Committee/Working Group meetings organised (2 per year)
- **D-C.5** 12 Core Group meetings organised (4 per year; face-to-face or teleconference)
- **D-C.6** Mid-term review organised
- **D-C.7** 2 international conferences organised

4.1.3 RISK ANALYSIS AND CONTINGENCY PLANS

The Management Committee and Core Group will be responsible for monitoring the overall progress of the Working Groups. Regular formal and informal communication within and between WGs will be key to detecting and mitigating potential problems. Four annual contact moments will be organised (face-to-face or via teleconference) between the members of the Core Group. MC meetings will be held at each of the main meetings, with additional communication on-line as necessary. Whenever problems are detected, the WG will immediately apply contingency measures, or, if necessary, hold additional meetings to identify and implement solutions.

The following table provides a detailed risk analysis:

Risk	Likelihood	Mitigation measures
Poor management of WGs	Low	<ul style="list-style-type: none"> • Selection of experienced and motivated WG leaders • Each WG will have a leader and co-leader • If poor management would occur, MC will provide enhanced support and if needed, replace (co)leader
Insufficient communication between and within WGs	Medium	<ul style="list-style-type: none"> • Regular informal contact will be motivated (e.g., Facebook, WhatsApp) • Implementation of fixed, formal moments for communication
Delay in WG deliverables	High for a minority of deliverables	<ul style="list-style-type: none"> • Strict monitoring of interim deadlines • Limited interdependence between deliverables both within and across WGs
Too few participants for Training Schools	Low	<ul style="list-style-type: none"> • Define scope of Training Schools in collaboration with MC and WGs • Explore online Training School options if participants' availability is limited

Too few candidates for Short-Term Scientific Missions	Medium	<ul style="list-style-type: none"> Active involvement of Early Career Investigators Designation of a STSM manager to supervise and support the STSM process
Lack of involvement of international organisations	Low	<ul style="list-style-type: none"> Currently a number of key international organisations have already expressed interest Different levels of involvement of international organisations are possible, from active participation to one-time invitation as keynote speaker
Lack of involvement of stakeholders	Low to Medium, depending on country	<ul style="list-style-type: none"> The importance of burden of disease is widely acknowledged by various stakeholders The Action participants will use their personal network to involve (national) stakeholders

4.1.4 GANTT DIAGRAM

	year	1				2				3				4			
		quarter				1	2	3	4	1	2	3	4	1	2	3	4
Core group																	
D-C.1	Website development	█															
D-C.2	BOD studies database	█	█														
D-C.3	Communication material	█	█														
D-C.4 ¹	MC meeting kick-off	█															
D-C.4 ²	WG/MC meetings			█		█		█		█		█		█		█	
D-C.5	CG meetings	█	█	█	█	█	█	█	█	█	█	█	█	█	█	█	█
D-C.6	Midterm review								█								
D-C.7	International conference								█								█
WG1: NCDs and injuries																	
D-1.1	BOD studies compilation	█	█	█	█	█	█	█	█	█	█	█	█	█	█	█	█
D-1.2	BOD researchers involvement	█	█	█	█	█	█	█	█	█	█	█	█	█	█	█	█
D-1.3	Workshop				W												
D-1.4	Training School								TS								
D-1.5	Short-Term Scientific Missions ^a			M			M					M				M	
D-1.6/7	Scientific output									█	█	█	█	█	█	█	█
WG2: Communicable diseases																	
D-2.1	BOD studies compilation	█	█	█	█	█	█	█	█	█	█	█	█	█	█	█	█
D-2.2	BOD researchers involvement	█	█	█	█	█	█	█	█	█	█	█	█	█	█	█	█
D-2.3	Workshop						W										
D-2.4	Training School										TS						
D-2.5	Short-Term Scientific Missions ^a			M			M			M				M			
D-2.6/7	Scientific output									█	█	█	█	█	█	█	█
WG3: Risk factors																	
D-3.1	BOD studies compilation	█	█	█	█	█	█	█	█	█	█	█	█	█	█	█	█
D-3.2	BOD researchers involvement	█	█	█	█	█	█	█	█	█	█	█	█	█	█	█	█
D-3.3	Workshop									W							

D-3.4	Training School					TS														
D-3.5	Short-Term Scientific Missions ^a			M					M					M						M
D-3.6/7	Scientific output																			
WG4: Methodology																				
D-4.1	Workshops					W														W
D-4.2	Checklist																			
D-4.3	Roadmap																			
D-4.4	Training material																			
D-4.5	Training School																			TS
D-4.6	Short-Term Scientific Missions ^a																			M
D-4.7	Joint research agenda																			
WG5: Knowledge translation																				
D-5.1	Compilation good practices																			
D-5.2	Workshops																			W
D-5.3	Roadmap																			
D-5.4	Toolbox																			
D-5.5	Training School																			TS
D-5.6	Short-Term Scientific Missions ^a																			M

^aShort-Term Scientific Missions will be organised according to needs and possibilities and may be organised in parallel. The timing presented here only reflects the planned distribution across Action years.

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