

Towards Joint Programming in Research : a pilote initiative on combating neurodegenerative diseases, in particular Alzheimer's disease.

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Today in Europe, only about 5% of the total public funding of research is used in common among European countries through the 7th Framework Programme for Research and Technological Development, and about 10% to support intergovernmental schemes or organisations. Conversely, 85% of these budgets are spent on national programmes exclusively. When we compare to the US, despite competences and skills distributed all over Europe and producing high quality research, Europe appears especially fragmented and less efficient. One research field which appears among the most affected ones by a reduced level of investment, a high degree of fragmentation and a default of overall coordination is related to dementia and Alzheimer's disease.

Alzheimer's disease is a common neurodegenerative disease which progressively and ineluctably destroys brain cells. It firstly affects memory and thinking, induces changes of mood, disorientation in time and space and finally disintegrates personality. About one person in 20 over the age of 65 suffers from dementia. Epidemiologists estimate that the number of people in Europe with dementia is around 5.5 million, a number which for those over 60 is expected to increase to 10.7 million by 2040. Dementia-related healthcare costs already exceed 80 billion Euros in the EU. This description of such a disease which may be considered as the most worrying medical and social question that will affect our societies in the coming years remarkably contrasts with the low levels of indicators and research investment of the European States.

Conversely to clearly delimited research programs like the Human Genome Project (3 billions base pairs to sequence and align), Alzheimer's disease understanding requires more extensive approaches and exchanges of researchers from different fields. How could we, as European States, build a new way of efficient collaboration to tackle such a major medical, societal and economic challenge? What resources could we mobilise despite the deep financial and economic crisis that has been affecting public budgets of European countries for now one and a half year?

The basis of a new era for European research

Eighty five percents of public research budgets of European countries are fully controlled at a national level, with probably less than 1% of the amount being reoriented to collaboration or coordination between countries. As a consequence, individual national research programmes may unnecessarily duplicate each other from an international perspective. Although a limited experience with transnational calls for proposals becomes available from e.g. Nordic or German-speaking countries, as well as within the ERA-NET scheme, the diversity and complexity of national procedures largely preclude the setting up of cross-border programmes and discourage researchers from accessing research funding across borders. Thus no real collaborative European endeavour is easily conceivable to tackle a societal challenge on the scale at which neurodegenerative progression and the development of dementia and Alzheimer's disease take place. The point is to encourage that a fraction of those budgets be spent on same objectives, however in a reasonably integrated way between countries willing to share risks and benefits on a much larger scale.

To provide a method allowing this calculated sharing to be organised, a communication to the European Parliament, the Council, the European Economic and Social Committee and the Committee of Regions was published in July 2008 by the Commission introducing a new concept of collaboration among owners of national research programmes: this is joint programming. It can be defined as "a process in which Member States define a common vision and a strategic research agenda, in order to address a major societal challenge for which the scale and the scope of their national programmes alone may not reach adequate proportions. "Participation of Member States and Framework

Programme Associated Countries in such a process is carried out "on a voluntary basis and according to the principles of variable geometry and open access".

This communication was published just after France accessed to the Presidency of the European Union for 6 months. Almost simultaneously, the President of the French Republic, Nicolas Sarkozy, decided to make the fight against Alzheimer's disease and related disorder a national priority, through a global mobilisation of medical, social and research forces. The French Minister of Research and Higher Education, Mrs Valérie Pécresse took the opportunity of this announcement to set up a working group, which she personally headed, entitled "The Health Challenge of an Ageing European Population : Fighting Degeneration" in Versailles during the informal Competitiveness Council organised in Versailles, 17th July 2008.

This working group agreed on the urgency to act in an ageing Europe upon the challenge due to the explosion of neurodegenerative diseases, and it recommended that the Member States under the Competitiveness Council, would launch a joint programme of research on these diseases, combining socio-economic and medico-biological issues.

What is joint programming?

Joint programming is neither another programme, nor any new tool to add to the extensive tool box of the existing national, intergovernmental or Framework Programmes. As a matter of fact, Joint Programming is not about spending the money, but about assigning the money. In a programming cycle, implementation comes last, and results from strategic steps which include horizon scanning, scenarios and impact assessments, budget arbitrations, prioritisation, evaluations, criteria and indicator setting. Joint Programming covers those steps, however in a specific configuration of countries willing to go together for the same ambitious objective.

Collaborative tools from the participating countries, or those developed in Framework programmes 6 and 7 as e.g. ERA-NETs or Art.169 initiatives, may be used as appropriate but will come last in an effort by national decision-makers in research to agree on a common agenda, commit themselves on their share in it, and define common rules by which resources and benefits are fairly distributed within the partnership. The primary goal of joint programming is to allow a synergistic use of shrinking research budgets in the difficult economic climate. It relies on the evidence that grouping calls for grants among several European countries will reinforce the potential for scientific collaboration with first class researchers and will allow to raise the level of ambitions in the face of known threats in Europe. Despite a separate attribution of funds from each country, a single scientific evaluation of projects has to be set up through an international peer-review process.

Joint programming addresses the accountability of governments to stakeholders in pooling research efforts to address common societal issues in Europe in the most efficient way. The Council Conclusions of 2nd December 2008 on "Joint programming of research in Europe in response to major societal challenges" provide unambiguous statements in this regard. One of the criteria for embarking into a joint programming approach, the Council conclusions say, is a demonstrated potentials of translating the output of public good research into benefits of European citizens and European competitiveness. The same Conclusions underline that Joint programming is a process which is led by Member States and that the role of the European Commission is to facilitate the identification process and to provide support as necessary.

Given the condition of "voluntary basis", the participating countries may decide in common the governance they consider best fit, and have a chance to strongly simplify the European procedures governing scientific collaboration (and its administration) that already exist in Europe through Framework programmes.

In its communication, the Commission proposed a pragmatic methodology for achieving Joint Programming through a step by step procedure. Three main stages can be identified: the development of a common vision; the translation of this common vision into a strategic research agenda (SRA) ; the implementation of this SRA under an adequate management structure. The Commission recommends also to develop these three stages within a series of framework conditions defining coherent approaches to procedures for peer review, shared methodologies for forward-looking activities and for

joint evaluation of national or regional programmes or investments. An important issue is the definition among national or regional authorities of common principles for funding cross-border research and of effective measures to ensure the protection of intellectual property rights and facilitate the dissemination and optimal use of research outputs.

Fighting neurodegeneration and particularly Alzheimer's disease

Given the magnitude of the impact of neurodegenerative diseases on ageing, which is dominated by Alzheimer's disease, a European mobilization of research on this topic would accelerate the provision of solutions in the biological, health, and social fields. This vision is shared by almost all countries having to face the ageing of their populations as demonstrated by the recent deep investment decided by France, Germany or United Kingdom.

The ultimate goal is obviously to find a cure of the disease and to enable early diagnosis for early, targeted treatments. However, the time necessary to reach this goal is not predictable. In the meantime, it is essential to implement solutions that can alleviate, even partially, the plight of families and the economic burden brought about by the increasing prevalence of this disease in our ageing populations.

All these elements constitute the bases of a shared vision on which a SRA will have to be built. This SRA must address three main challenges.

The first challenge is scientific. Although our understanding of the mechanisms of the disease has greatly improved over the past few years, we are far from the full picture and there is no immediate prospect of finding therapies that may be effective in slowing or halting disease progression. For instance, researches on genetic susceptibility, competitive animal models or new biomarkers must be supported.

The second challenge is medical. The general practitioners, specialists, and other caregivers have at their disposal batteries of tests, from simple to more complex, to clinically explore brain function and help establish a diagnosis. However, the organization of the care system at all stages of the disease needs further consideration. How is the relationship best managed between those involved in diagnosis, symptom management and social care as the disease progresses from a medical problem into a medical and social problem? What therapeutic strategies (both drug and non-drug) have demonstrated effectiveness in appropriate randomized studies? Do we have clinically meaningful endpoints, for example, is effectiveness judged according to the comfort of the sick, of those who live with her or him, or on the judgement of the evolution of the disease, or even on a recovery which is for now so far out of reach?

The third challenge concerns social care and health services. An environment must be created around the patient and his/her family, which adapts to the evolution of abnormal behaviour in everyday life. For instance, home automation, smart homes, domotics must be developed. Simple life site development and support for caregivers at the onset of illness, this adaptation mobilizes gradually more and more energy and skills. At what stage should one consider leaving its house for life sites? And how would these structures be organized with enough trained and valued staff, able to deal with conditions of varying severity?

State of play of the pilot Joint Programming Initiative on combating neurodegenerative diseases, in particular Alzheimer's disease

A declaration of intent describing the three steps above has been approved by 11 States and within the last six months 21 countries have officially joined the initiative (France, UK, Germany, Italy, Spain, Ireland, Denmark, Czech Republic, Sweden, the Netherlands, Finland, Portugal, Hungary, Greece, Poland, Belgium, Slovak Republic, Luxemburg, Lithuania, Turkey, Albania).

A management structure has been set up that met on 18th June, 2009. A list of clear and realistic scientific, medical and social objectives will be proposed by an outstanding international scientific advisory board composed of fifteen top-ranking scientists from all over the world. A strong willingness

exists to coordinate similar programmes aiming at transnational European added value while not undermining existing opportunities and avoiding unnecessary duplication with national programmes

The fight against neurodegenerative diseases and in particular Alzheimer's disease is a pilot project which should be soon followed by other initiatives opening new ways of "à la carte" collaboration within European countries, based upon efficiency and excellence of research.

Perspectives and discussion issues

This pilot Joint Programming Initiative on combating neurodegenerative diseases, in particular Alzheimer's disease helps to dig out questions. As all new concepts, this strategy of collaboration within European countries needs to be adopted by the stakeholders and careful attention should be given to all legitimate fears and questions.

Indeed several issues should be discussed. For instance:

- Should countries rather privilege societal challenges where their national research is strong or ones where it is less competitive ?
- What is the link with national mechanisms for research programme definition and agenda setting ?
- Does the existence in a given country of strategic national programmes and priorities facilitate or hinder a Joint Programming approach ?
- Should a Joint Programming approach be adapted to fit with the different national research systems ?
- Is Joint Programming adding to the momentum for preceding or on-going reforms of the national research and innovation systems?
- Are expected benefits from Joint Programming particularly size-specific (e.g. Are benefits for large and small countries possibly of different nature)?
- Is there a conceivable benefit for countries not to participate in a given JP initiative run by others?
- What would be the role in Joint Programming of Research Performing Organisations (e.g. the German DFG , the British MRC, the French Alliance, the Cnrs...) and Universities? How to combine their rather bottom-up approach to the more strategic approach of Joint Programming ?
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The answers to these questions and others that will appear as Joint Programming initiatives will progress are essential to the success of this new strategy. The ultimate goal of all this work is to lead to new initiatives around research excellence intended to offer a competitive and attractive image of European research prosecuted for the greatest benefit of Europe's populations and economies.

References

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