



# **Experts Meeting**

## **on Organ Donation and Transplantation**

### **Action Plan**

**11-12 March 2009**

### **Summary report**

The first meeting of national experts on the Organs Action Plan was convened on 11 and 12 March 2009 under the Chairmanship of Mrs Patricia Brunko, Head of Unit, SANCO C6.

All Member States except the Czech Republic and Slovakia were present at the meeting; were also present: experts from Norway, Switzerland, Croatia, and the Council of Europe were also present. Eurotransplant and Scandiatransplant were also present.

#### **1. WELCOME AND INTRODUCTORY REMARKS BY THE CHAIRMAN OF THE COMMITTEE**

The Chairperson welcomed the delegations. The aim of the meeting was to discuss the objectives and priority actions of the Action Plan; to have an exchange of views on the working methods and finally to identify and prioritise areas of actions. In particular identify priority actions for the next two years and determine the creation of specific technical working groups.

#### **2. ADOPTION OF THE AGENDA**

The agenda was adopted without changes.

### **3. PRESENTATION OF THE DELEGATIONS**

Each delegation presented a brief overview of its structures, related responsibilities, and underlined the main developments since the last competent authorities meeting.

### **4. DISCUSSION ON THE CONTENT OF THE ACTION PLAN**

The Commission presented the content of the Action Plan to the participants.

### **5. THE COMMISSION WORKING METHODS – INTERNAL WORKING METHOD OF THE GROUP OF EXPERTS**

#### **5.1. The Meetings of national representatives for the Organs Action Plan**

Commission presented the internal working methods of the group of experts. In particular it was pointed out that regular meetings organised by the European Commission should be held. Participants in these meetings will include representatives from all 27 Member States, EEA, 3 candidate countries (Turkey, Croatia, fYRoM), Eurotransplant, Scandiatransplant, the Council of Europe and the WHO.

These meetings, at least for the first years, would need to take place twice a year. In 2009 the second meeting will be held in November.

These meetings would provide an opportunity for Member States to discuss and exchange ideas, experiences, information and best practices with each other.

#### **5.2. Technical working groups**

The Commission pointed out that specific objectives and deliverables of the Action Plan need further preparatory work and forward planning. The Commission therefore proposed the establishment of technical working groups. These shall be created on the basis of the actions and objectives in the Action Plan prioritised in this meeting. Technical working groups shall prepare technical documents to be discussed and presented in the following Plenary Action Plan meetings.

These technical working groups who would be composed by the experts participating in the Action Plan meetings and declare their interest to participate during the course of this first meeting. The Commission recommended that the size of each technical working group would be flexible enough to allow the attainment of the best possible results. Ideally each working group will be composed by at least five (5) experts.

The Commission proposed the creation of an IT-tool to coordinate and facilitate their work in between meetings.

The Commission shall closely follow the work/progress/results of the working groups.

#### **5.3. Indicators/Benchmarking**

Member States agreed to establish a common set of indicators to monitor organ policy and a methodology to evaluate the potential in each Member State. Common definitions

of both terms and methodology need to be adopted in order to evaluate the results of transplant systems.

Member States agreed upon the creation of a technical working group to elaborate on the aforementioned topic. Nevertheless it was made clear throughout the discussion that the aim of the technical working group would not be to duplicate the work done in the Council of Europe in this respect and should be based on the conclusions of two existing European projects; namely Alliance-O and DOPKI.

#### 5.4. Set of National Priority Actions

The Commission suggested that Member States work on the basis of a Set of National Priority Actions. These would serve as a tool in order to implement the suggested objectives and priority actions of the Action Plan. Member States will prepare their Set of National Priority Actions and will present them to the next meeting in November. The Commission will provide MS with a form to be filled in and submitted before the November meeting.

The Set of NPA shall be country-specific and tailor-made to the specific situations of each different Member State. They shall therefore incorporate those actions identified as essential for achieving the common goals of the Action Plan according to the specificities

## **6. DISCUSSION OF PRIORITY ACTIONS PROPOSED IN THE ACTION PLAN**

### 6.1. Deceased Donation - Priority Actions 1 and 2

The success of some Member States in increasing organ availability has been largely due to the organisation of the process, which shows that some ways of organising the organ donation process might be better suited to achieving high availability of organs than others. The combination of an efficient system for organ donor identification, detection and procurement has been identified as one of the keys to increasing deceased donation. In particular, the presence of a transplant donor coordinator, whose main responsibility is to develop a proactive donor detection programme, is the most important step towards optimising organ donation and improving donor detection rates.

Of equal importance is to promote Quality Improvement Programmes for organ donation. These programmes are primarily a self evaluation of the whole process of organ donation according to the characteristics of the hospital and the health system. These will make it possible to compare results and thus to identify areas for improvement.

Member State experts from Spain, Austria, Belgium, France and the UK presented their experiences and the current and future practices on the issue.

It was decided to create a technical working group on deceased donation encompassing both of the above-mentioned elements. Nevertheless MS insisted on the fact that this technical working group would not duplicate the existing work undergone in the field. The aim of this technical Working Group is to transfer best practices, disseminate

existing results and tools (i.e. ETPOD project), provide guidance to Member State that request it but also concretise such practices.

## 6.2. Living Donation - Priority Action 3 (Objective 2)

Being complementary to deceased donation, living donation is an alternative to improving the availability of organs for transplantation. The Commission advised Member States to deploy the Action Plan in order to promote the exchange of best practices on living donation programmes. This includes the promotion of living donation programmes and the development of registration practices – as foreseen in the Directive.

Presentations were given by Member States with high living donation rates describing their experiences and systems. A presentation of the Public Health Programme Project EULID (European Living Donation and Public Health) followed.

Participants agreed to postpone the creation of a technical working group on the topic of living donation until 2011.

## 6.3. Increasing Public Awareness - Priority Actions 4 and 5

### **i) Communication**

Various approaches have been identified as to how Member States use communication means in respect to organ donation and transplantation; these range from heavy media financing and investment to no financing at all. In order to provide better insight to Member States presentations of different approaches and perspectives were provided.

A large majority of Member States seem to be in agreement with the fact that structural changes in the organisation of transplantation systems and informing the media have greater positive impact to increasing donation rates than public awareness campaigns.

Member States agreed that currently they saw no usefulness in the establishment of a pan-European public awareness raising campaign.

### **ii) Identification of donors**

The Action Plan lists the need for EU citizens to be well informed about rules on organ donation in the different Member States because of their increasing mobility.

## 6.4. Twinning of projects - Priority Action 6

Two presentations were provided on twinning of projects providing two separate models. The first one was the "EU PHARE TWINNING PROGRAMME" between Slovakia and Italy which aimed at the improvement of the safety, quality and availability of organs, tissues and cells for transplantation. The second presentation focused on the ways Eurotransplant helps set up and/or support transplantation systems either in or outside the eurotransplant region.

The Commission reminded Member States the existence of TAIEX as a potential tool to support such projects in the future.

#### 6.5. Structural Funds- Priority Action 6

The Commission made a brief presentation to the participants regarding the possibility to use Structural Funds in order to support and strengthen transplantation systems and infrastructures.

European regional policy is designed to bring about concrete results, furthering economic and social cohesion to reduce the gap between the development levels of the various regions. This policy helps to finance, through the Structural Funds, concrete projects for regions, towns and their inhabitants. The idea is to create potential so that the regions can fully contribute to achieving greater growth and competitiveness and, at the same time, to exchange ideas and best practices. For the period 2007-2013, investment in health has been tagged as one of the factors contributing to this general policy objective. For further details on the general objectives of the Regional policy and structural funds can be found at: [http://ec.europa.eu/regional\\_policy/policy/why/index\\_en.htm](http://ec.europa.eu/regional_policy/policy/why/index_en.htm).

Inclusion of investment in health in the objectives pursued by the regional policy for the period 2007-2013 creates concrete opportunities for the health sector, and in particular the transplant community, in terms of fund raising for strengthening infrastructures or human resources. Furthermore, some cross-border/trans-national transplant related activities could be candidate for support by some instruments of the Structural Funds. The prioritisation of investments in health or other sectors is the decision of Member States. This phase took place in 2007 and is now finalised. The description of the 27 Member States Operational programmes can be found at: [http://ec.europa.eu/regional\\_policy/country/prordn/search.cfm?gv\\_pay=ALL&gv\\_reg=ALL&gv\\_obj=ALL&gv\\_the=ALL&lan=EN&gv\\_per=2](http://ec.europa.eu/regional_policy/country/prordn/search.cfm?gv_pay=ALL&gv_reg=ALL&gv_obj=ALL&gv_the=ALL&lan=EN&gv_per=2).

The Commission encouraged the Delegations to coordinate with their respective Ministries of Health and ensure that structural funds available in 2007-2013 can be used for the concrete development of the transplantations capacities and activity at country, or even trans-regional/national, levels. The Commission also advised the delegations to be involved in the preparation of the next multi-annual programme 2014-2019 to secure the presence of health investment in the Regional policy objectives.

#### 6.6. EU-Wide Agreements - Priority Action 7

A cooperation method is the ideal context to discuss issues of mutual concern and come up with common ideas and shared solutions.

As regards patient mobility the Commission referred to the ongoing discussions of the Proposed Directive on the application of patients' rights in cross-border healthcare. Certain Member States expressed their concerns regarding the inter-relationship of the two Commission proposals.

Regarding organ trafficking it was agreed that the issue is currently adequately addressed in the Council of Europe. The Commission drew the attention of the participants to the recently adopted Framework Decision on preventing and combating trafficking in human beings, and protecting victims, repealing Framework Decision 2002/629/JHA. The

abovementioned Framework Decision includes organ trafficking as one of the offences covered.

Other issues will be further discussed in the next meetings.

#### 6.7. Interchange of organs - Priority Action 8

The exchange of organs between Member States is already common practice; nevertheless large differences between the number of organs exchanged between Member States which set up bodies and/or rules for the international exchange of organs; (such as Eurotransplant and Scandiatransplant and other Member States that do not have bilateral agreements). These differences indicate that the full potential of exchanging organs has not yet been reached. This is problematic as the cross border exchange of organs has clear benefits.

As this holds particularly true for difficult to treat patients (paediatric, urgent or hypersensitised patients that require very specific matching) and small Member States, DG SANCO has launched a call for tender on the specific issue, in order to identify the appropriate methodology.

A large number of Member States strongly supported the idea of exchanging organs and stressed the necessity to do so; they pointed to the benefits such practices have had in the past and to potential advantages. Certain Member States, nevertheless pointed to the fact that due to their size and developed nature of their transplantation systems such exchanges have no added value.

Most Member States were also positive towards the idea of the tender, regardless of whether or not this would directly produce benefit them. Participants realised that such a tender would provide an added value to a number of Member States.

#### 6.8. Evaluation of post-transplant results - Priority Action 9

A presentation of the EFRETOS Public Health Programme was provided by the leading partner in the project, Eurotransplant. The objective of EFRETOS (European Framework for Evaluation of Organ Transplants) is to define common terms and methodologies to evaluate the results of transplantation, by setting up a tool for the follow-up of transplantation results. The project will provide a common data dictionary, defining methodology and legal and technical requirements for registry management.

#### 6.9. Common accreditation systems - Priority Action 10

Due to lack of time the discussion was postponed to November.

Patricia BRUNKO

Chairman of the Committee





