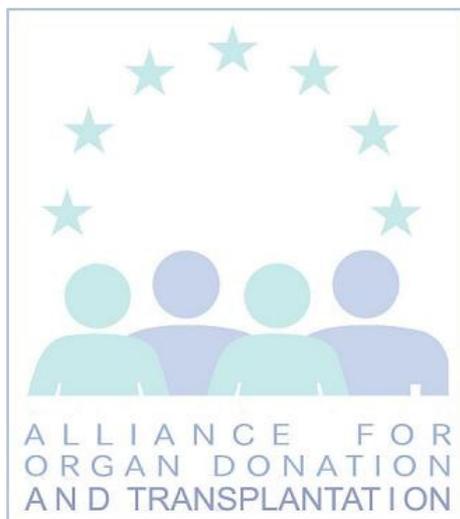


**ERA-NET SCHEME  
COORDINATION ACTION**



**ALLIANCE-O**

**European Group for Coordination of National Research Programmes on Organ  
Donation and Transplantation**

Project/Contract Number: 0011853

**Work Package 6:  
Fundamental research linked to organ donation**

**Deliverable 6.2.  
Proposal of strategies to improve efficiency of fundamental research  
Position Paper**

## Work Package Leader: DSO, Germany

<b>Participant name</b>	<b>Abbreviation</b>	<b>Country</b>
Agence de la biomédecine	ABM	France
Deutsche Stiftung Organtransplantation	DSO	Germany
Hungarotransplant	Hu-T	Hungary
Centro Nazionale Trapianti- Istituto Superiore di Sanita	CNT-ISS	Italy
Organizaçao Portuguesa de Transplantaçao	OPT	Portugal
Centro Nacional de Trasplantes y Medicina Regenerativa	CENATMER	Spain
UK Transplant	UKT	United Kingdom

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## **I. Introduction:**

Based on the collection and evaluation of all the information about the research landscape with particular focus on organ transplantation in the seven European Countries and based on an inventory of over 500 Research Projects in the field of organ transplantation in those countries two workshops were dedicated to prepare a position paper for a proposal of strategies in order to improve the efficiency of fundamental research.

The first workshop in November 4<sup>th</sup> 2006 in Neu-Isenburg, at the DSO headquarters was dedicated to analyse the findings of the inventory based on the categorized projects.

A1	Epidemiologic Studies
B2	Alloreactivity and Tolerance
C3	Preservation, Ischemia
D4	Alternative Therapies/Treatments
E5	Complications & Co morbidity
F6	Acute and chronic failure of the graft
G7	Immunosuppression/Immunology
H8	Quality and Safety of organ transplantation
I9	Quality of life and socio –economic impact
J10	Socio-cultural-legal – economic-ethical-religious etc. aspects of organ donation/transplantation
K11	Transplantation potpourri (for everything that does not fall within any category but still is of interest and importance)

We looked at several categories in detail based on the information gathered on each project within one category and also country by country.

However the set of data available as information on the individual projects differed immensely. It differed not only from country to country but also on the national scale the data set available on each project showed a lot of diversity. Due to this heterogeneous project landscape it is not viable to identify main focuses or possible duplication.

Therefore we also looked at the total of projects and their representation within each category as showed once more in the general overview. All categories we chose are represented:

## General Overview:<sup>1</sup>

Code	Category	France	Germany	Hungary	Italy	Portugal	Spain	UK
A1	Epidemiologic Studies	0	6	3	5	0	17	0
B2	Alloreactivity and Tolerance	4	14	0	3	2	23	0
C3	Preservation, Ischemia	8	33	1	4	4	14	4
D4	Alternative Therapies/Treatments	17	9	11	3	0	11	0
E5	Complications & Co morbidity	5	5	6	4	0	20	0
F6	Acute and chronic failure of the graft	6	19	1	4	3	24	0
G7	Immunosuppression/Immunology	51	25	2	2	9	12	0
H8	Quality and Safety of organ transplantation	15	5	0	2	0	0	2
I9	Quality of life and socio - economic impact	1	1	1	0	0	7	0
J10	Socio-cultural-legal - economic-ethical-religious etc. aspects of organ donation/transplantation	14	2	1	1	0	0	2
K11	Transplantation potpourri (for everything that does not fall within any category but still is of interest and importance)	9	49	2	8	3	0	3
	<b>TOTAL</b>	<b>138</b>	<b>168</b>	<b>28</b>	<b>36</b>	<b>21</b>	<b>128</b>	<b>11</b>

<sup>1</sup> Figures on the projects that have been collected.

We had to acknowledge that the projects we collected are probably only the top of the iceberg and that the number of existing projects can not even be estimated. This results from various facts:

- Fundamental research in organ transplantation covers a very wide range of interdisciplinary fields with regard to medical science.
- Funding of research is not just in the public domain, on the contrary universities and research institutes depend to a large extent on private funding.
- Private funding institutions however are often reluctant to reveal what they are currently supporting.
- Pharmaceutical Industry itself conveys and funds a lot of research in the field of organ transplantation however they have little interest to inform about their current research projects.
- Scientist themselves, based on their fundamental right of freedom in research, are reluctant to reveal what they are currently investigating.

We also had to acknowledge that an analysis of the projects we collected as far as the contents and topics of the research projects are concerned would not be target oriented. For several reasons, as stated below, it would neither be possible nor would it be responsible to identify main focuses and basic needs:

- There exists temporary fashion that often leads to funding of certain topics such as Xenotransplantation or biotechnology
- A lot of public bodies use the so called preer-review when determining who will receive a grant for research rather than on the contents and the needs
- The levels of funding differ immensely which makes a comparison very difficult

## **II. Approach:**

Hence it became apparent that a different approach would be needed in order to meet the requirements of this deliverable. There was a general consensus of all participants that we would be able to benefit from the experiences made and difficulties we encountered in collecting the necessary data for the inventory on a different level and our proposal is only a logical consequence of our experience during the past 12 months.

For this purpose a second workshop was held in Paris on March, 16<sup>th</sup> 2006 at the ABM Headquarters.

Since apart from Spain and France there exists no national body in the participating countries that would be dedicated exclusively to the organisation and coordination of research in the field of organ donation, procurement and transplantation, the question was raised whether there is a need for such an institution already on a national level. The response was affirmative.

Thereafter all participants of the workshop were invited to discuss what functions or qualities the national bodies should fulfil and what could be the additional benefit to create a network of those institutions even on a European level and what exigencies it should preferably meet.

## **III. Conclusions**

After a very fruitful discussion the participants found a general consensus on what should be the key tasks, functions and responsibilities of a national body dedicated to research in the field of donation, procurement and transplantation. It goes without saying that the establishment of the national body would have to be in accordance with national and European legislation:

- ❖ Take into consideration national peculiarities and legislation.
- ❖ Allow for a multidisciplinary approach.
- ❖ Be an independent body.
- ❖ Be a source of information (open to everybody).
- ❖ Coordinate research and offer services that facilitate cooperation and communication (classic and innovative communication and information tools: e.g. links, data base; newsletter; congresses; workshops, platform; forum).
- ❖ Take care of public relations and dissemination.
- ❖ Where possible, provide funding of research activity.
- ❖ Enhance transparency and trust in research.

In the ideal case this national body would evolve to become the first address where research program makers and sponsors as well as scientist and research institutions would turn to with any question related to research in the field of organ donation, procurement and transplantation.

Taking into consideration that nowadays research is not limited to national boundaries and also that fields of research exist where it might be indispensable to cooperate beyond those boundaries (e.g. in circumstances where there are a small number of cases in each country) a Europe-wide network of the national organisations was proposed for discussion during the second half of the workshop. Again responses were unanimously positive.

All the qualities required for the national body most certainly are also relevant when taking it a step further and lifting it to a European level.

However we can not call for a European network without pointing out the additional benefit of such a network. The benefits become apparent when we look at the results of our discussion and the consensus finding of the participants as far as the additional purposes of the European Network should ideally be:

- ❖ Define goals and benchmarks in order to oblige national authorities to take actions and measures in the following areas:
  - Improve organ donation and transplantation
  - Transplant outcomes (define levels of excellence)
  - Living donation
  - NHBD
  - Conversion rate
  - Islet transplantation (cells)
  - Xenotransplantation
  - Others
  
- ❖ Focus on fields where it is indispensable to cooperate (e.g. small number of cases)/coordinate the use of infrastructure
  
- ❖ Enhance European competitiveness

#### **IV. Further Steps:**

Based on the findings above we therefore suggest a two-step-approach in order to improve efficiency of fundamental research linked to organ donation, procurement and transplantation.

Representatives from each country without a national body dedicated to this particular field of research should consider how to provide a facility for the coordination of research in order enhance the performance of research in this important field of medicine.

On the European level a proposal for a European transplant research network needs to be developed that would link the national bodies and fulfil the tasks as stated above.