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Work Package 2:
Expanding donor pool

Deliverable 2.3: Position paper on promotion of organ donation

Work Package Leader: ONT. Spain

<i>Participant name</i>	Abbreviation	Country
Agence de la Biomédecine	ABM	France
Deutsche Stiftung Organtransplantation	DSO	Germany
Hungarotransplant	Hu-T	Hungary
Centro Nazionale Trapianti	CNT	Italy
Organizaçao Portuguesa de Transplantaçao	OPT	Portugal
UK Transplant	UKT	United Kingdom
Organización Nacional de Trasplantes	ONT	Spain

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I. INTRODUCTION

Organ transplantation has become a common lifesaving and life-enhancing procedure with excellent results. The improved success rates, due to the advances in technology and immunosuppression have contributed to a substantial increase in the number of patients waiting for a solid organ transplant. However, the number of deceased donors and organs for transplantation has not increased at the same rate. The result of this situation is an increasing gap between the number of patients waiting for a transplant and the number of patients who are indeed transplanted each year.

Deceased organ donation, primarily based on donation after brain death, faces a numerical limitation, represented by the fact that no more than 1% of death people and no more than 3% of people who die in a hospital hit this situation (1). Keeping in mind this first limitation, the potential of deceased donation after brain death is very difficult to reach, since organ donation and procurement is a very delicate and complex process, that needs the cooperation of many actors and that can be broken at any time. Even more, the whole process of organ deceased donation must take place in a very short period of time, a characteristic what enhances the weaknesses of the process itself. Several basic steps may be identified in this process, as outlined in ALLIANCE-O project (Deliverable 4.3: State of the art of quality systems): Identification of the potential donor, diagnosis of brain death, asking for consent/authorization to proceed with donation, maintenance of the donor, screening/evaluation of donor's suitability, feed-back and support to the families, evaluation of organ's suitability, coordination of safety and transport and retrieval and preservation of the grafts.

Asking for consent/authorisation to donate is a step that outlines one of the features of organ transplantation: it represents a therapeutic alternative that needs the society's contribution. This means, the undeniable difference between transplantation and other health-care activities consists on the necessity of donation. Society's attitude towards organ donation is very much dependent on the information they receive about this issue, information that can be actively generated from transplant organizations, from the mass media and from the health-care workers, among others.

The loss of potential donors produced by a family barrier that makes impossible the donation is one of the challenges we had to face up to without delay. When

estimated over the number of families approached, the rates of refusals to donate have been described to be well over 40% in some European and other surrounding countries (2) (figure 1). In programmes evaluating the performance of procurement hospitals in the donation process, refusals to donate represent a clear obstacle from a brain death person not becoming an actual donor. This is, for instance, the case of the Quality Assurance programme in Spain. From the analysis of cumulated results from the period 1999-2005, it was observed that 12.3 % of deaths occurring at the ICUs are brain deaths and that 50.8% of them become actual donors (3). The main reasons that justify that a potential donor (brain death person) does not become an actual donor are represented by medical contraindications (27.1%) and refusals to donate (14.7%).

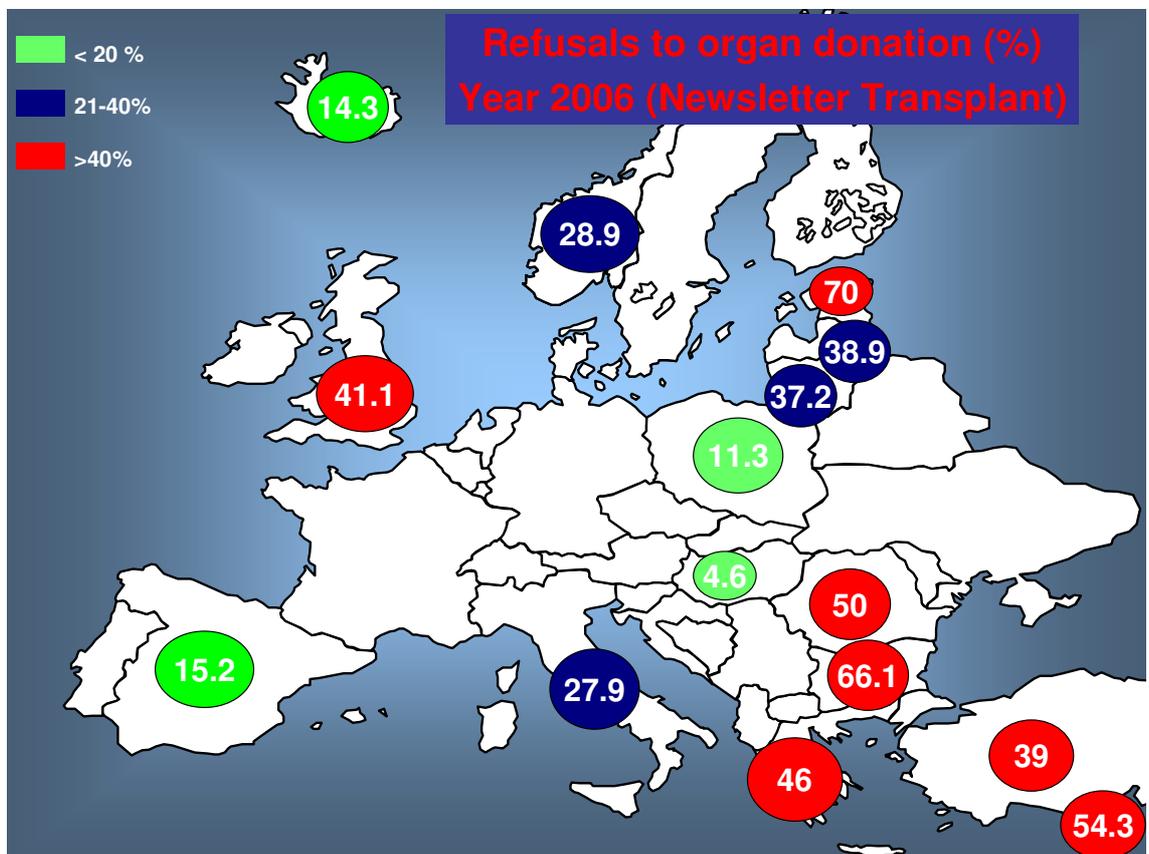


Figure 1: Refusals to donate (% of refusals over the number of family interviews). Newsletter Transplant 2007; 12 (1): 34. Spanish National Transplant Organization Web Site. Available at: www.ont.es Accessed August 27th, 2007.

Outstandingly, refusals to donate represent a problem whatever the consent policy applied in a country. From the work performed in WP 7 of ALLIANCE-O project, the consortium has understood that little differences exist between presumed (opting-out) or informed (opting-in) laws, in day to day practice. In reality, even those

countries with a presumed consent law always approach the family, as a way to understand what the wishes of the deceased were about donation or as a way of getting permission to proceed with donation, in case the wishes of the deceased were unknown. Even more, independently of the underlying policy, none of the countries acts against the wishes of the family in case there is a controversy between the wishes of the deceased about donation and those of the family.

Refusals to donate expressed in life reflect the opinion of one specific person as a result of individual (beliefs, personal experiences and others) and social circumstances (each individual represents the society to which belongs). Refusals to donate expressed through a family represent a more complex situation. On one hand, family members have their own opinion on donation (4). On the other hand, their final decision depends on the knowledge they had on the wishes of the deceased (4), the special circumstances in which the decision must be made and the way the family is approached. At this point, there is an external figure participating in the process: the professional in charge of the family interview.

Promotion of organ donation and transplantation includes a variety of actions and activities which are targeted to reduce refusals to donate, but mainly include those actions targeted to the society (and/or specific groups inside the society). The final objective of these actions is creating a favourable attitude towards organ donation, generating the understanding on the need of organs to develop the transplant programmes and ensuring the transparency and equity of the system.

II. OBJECTIVE

The objectives of the present deliverable are:

1. To review the state of the art in promotion and education on organ donation and transplantation, by describing the different activities and actions that have developed or are under development in countries within the consortium
2. To reflect the position of the consortium with regard to promotional activities on organ donation and transplantation

III. METHODOLOGY

A previous deliverable produced within WP2 (D 2.1-2.4) has quantitatively described a set of different promotional initiatives (under the denomination of educational and communication initiatives), aimed to expand the organ donor pool among ALLIANCE-O countries. In order to provide a more detailed description of these initiatives, a specifically designed questionnaire was filled in by all the partners. Subsequent discussions among the partners have helped to construct a common position of the group on promotion of organ donation and transplantation.

IV. STATE OF THE ART OF PROMOTION ON ORGAN DONATION AND TRANSPLANTATION

Promotional activities and actions on organ donation and transplantation which are running or have been performed in ALLIANCE-O countries are described in this section. According to the target to which these activities and actions are directed, they may be classified as follows:

1. General population as a whole
2. Special groups in the society, needing special attention with regard to the information (e.g. minorities) or because they represent multipliers of the provided information (e.g. mass media).
3. Health-care professionals, whether directly involved or not in the process of organ donation and transplantation.

1. Promotional and educational activities targeted to the general population

1.1. Surveys

Surveys targeted to the general population have been used as a diagnostic tool to understand and review the special promotional and educational needs of a population on donation and transplantation activities. Several issues have been explored through these surveys, as the degree of information on donation and transplantation, sources from which information is obtained, opinion on the way it would be desired to receive such information, attitude toward donation of own organs and organs of a deceased close family member, opinion on the procedures used to ask for consent to donate, discussion of organ donation within the family circle, opinion on the organ donor card and other tools to express the wishes on

organ donation and other issues. Even more, these surveys have also provided information on the profile of the person who is prone or who is not prone to donate and factors affecting this specific attitude.

A European Survey on organ donation and transplantation (5) has been recently conducted among 28,584 people in the EU member states and the acceding countries. National surveys targeted to the general population have been performed in four countries within ALLIANCE-O, in particular in France, Germany, Spain and United Kingdom. Besides, specifically designed surveys have been conducted to explore the aforementioned issues among students/teenagers in France and Germany. Details on these surveys are described below.

1.1.1. France

The Agence de la Biomédecine (ABM) led 2 surveys targeted to the French general population during the year 2006, one concerning the adult population over 18 years of age and the other concerning the teenagers and young adults, aged 16 to 25 years.

The main purposes of the survey targeted to the adult population were to define how the discussion on organ donation emerges within the family context, to point out the events that lead to that discussion and to explore the attitude of the French population towards organ donation.

The survey concerning teenagers and young adults aimed to evaluate their attitude towards organ donation, their level of knowledge on donation and transplantation, the figures to whom they talk about the subject and the way they would like to receive the corresponding information.

The results of both surveys were disseminated through the mass media in December 2006, a period corresponding to the first national information campaign targeted to the 16-25 years old population.

A previous survey conducted to the adult population in France dates from 1997.

1.1.2. Germany

The Federal Centre for health education (BZGA), which according to section 2 of the German Transplantation Act is in charge of the education of the population, also in terms of organ donation, has conveyed the following surveys targeted to the general population:

- Year 2001: General Report on the willingness to donate in Germany, where the following items were explored: discussion of the issue of organ donation, passive and active acceptance of organ donation, knowledge about and possession of the organ donor card and contact persons.
- Year 2003: Specific survey targeted to teenagers and young adults (14-24 years old) to explore the attitudes of this segment of the population towards organ donation.

Other surveys targeted to the general population, apart from the surveys conducted by the BZGA, have been performed in Germany:

- Years 1991/1994: Institut für Demoskopie Allensbach: Attitude towards donor card.
- Years 1997/1998: Emnid Institut [on behalf of Deutsche Gesellschaft für Humanes Sterben (DGHS)]: Attitude towards organ donation and transplantation.
- Year 2000: Institut für Demoskopie Allensbach [on behalf of Körper-Stiftung (Deutscher Studienpreis)]: Attitude towards possibilities of transplantation.
- Year 2004: Institut für Demoskopie Allensbach: Survey on attitude towards donor card.
- Dr. Decker, University of Leipzig: Attitude of the German Population towards organ donation.

1.1.3. Spain

A survey has been performed to a representative sample of the Spanish general population of 18 years of age or older at three different occasions (1993, 1999, and 2006). These surveys have been conducted by the Organización Nacional de Trasplantes (ONT) in collaboration with the Social Psychology and Methodology Department of the Psychology Faculty of Madrid Autonomous University.

The questionnaire applied (CAPD) was specifically designed by both organisms to explore the degree of information on donation and transplantation, the attitudes towards the donation of own organs and those of a relative and the communication in the family context, among other issues. This survey has also provided the opportunity of describing the profile of persons prone and not prone to donate, on the basis of demographic characteristics, educational level, social status, religious beliefs and level of information on donation and transplantation.

In spite of the development of several promotional and educational activities in the last years, there was an outstanding lack of change in the attitude of the Spanish general population towards organ donation in the 13 year period explored. For instance, the percentage of the surveyed who had a donor card or was prone to become an organ donor was 64.5%, 63.9% and 66.5% in the years 1993, 1999 and 2006, respectively, this difference not being statistically significant. A decrease in the rate of refusals to donate in the same period of time (from 25-27% to 15.2% in the year 2006) in spite of this lack of change may indirectly lead to the conclusion that a progressive improvement in the technique for the family interview has taken place, possibly as a result of the efforts in training of professionals in charge (5).

1.1.4. United Kingdom

UK Transplant (UKT) has conducted several surveys targeted to the general population and to particular segments of the population (e.g. black and minority ethnic groups, NHS staff), through telephone and face to face interviews and with a stratified random sampling by age/gender and ethnicity, since these factors had proven to be relevant. These surveys have been used to inform marketing strategies targeted at each group. Generic surveys demonstrate that 85 – 90% of the population support organ donation in principle. Surveys amongst black and minority ethnic (BME) groups have highlighted barriers to donation particular to these communities. Results from these surveys have helped inform bespoke marketing campaigns that use relevant formats and communication channels with messages designed to address fears and misconceptions with the aim of engendering positive attitudes (see below).

1.2. Publicity campaigns on organ donation and transplantation

Publicity activities and campaigns have been performed in most of the countries within ALLIANCE-O. Some information on these activities and underlying messages are described below.

1.2.1. France

Since 2001, the French ABM organizes the National Organ Donation day on June 22nd, a public awareness campaign. It mainly consists on obtaining articles in mass media, radio advertising, developing of information on the web site and providing informative brochures to the population, to give clear and accurate information on organ donation and transplantation.

Since 2006, ABM is developing specific actions towards the 16-25 years old population. Radio advertising has been complemented with informative material specifically designed to teenagers/young adults (specific information on the web site and brochures) and pedagogic material for teachers (as a DVD).

The aim of ABM campaigns are to encourage people to discuss on organ donation and transplantation and communicate their opinion within the family circle, respecting everyone's decision ("Organ donation, whatever you're against or for it, tell your family"), to give a clear and complete information to everyone and to raise the knowledge on donation and transplantation (shortage of organs, successes of transplantation, the French law and other issues).

1.2.2. Germany

The DSO organizes, together with different self-help groups, the annual German Organ Donation day, which is held the first Saturday in June.

Sometimes, one-day phone actions are coordinated with readers of certain magazines.

Specific actions with students have been carried out. In particular, in the year 2003, a school contest was carried out.

Various promotional campaigns to raise public awareness for the importance of organ donation have been performed.

1.2.3. Italy

CNT promotes every year the National Day of Organ Donation and Transplantation.

Different promotional campaigns with general population as a target have been developed at a local, regional and national level. These campaigns have mainly consisted on posters and videos, with the concept of altruism as the underlying message.

1.2.4. Spain

ONT organizes the National Day of Organ Donation and Transplantation on an annual basis, which is held on the first Wednesday of June. ONT ensures a press

conference and specific promotional activities are also performed at the regional and hospital levels.

Different promotional campaigns with general population as a target have been developed at a local, regional and national level, by the corresponding transplant organization. These campaigns have been mainly based on posters and brochures with brief sets of information, as well as on a DVD ("Hope"). Underlying messages are based on the concept of altruism and reciprocity.

1.2.5. United Kingdom

UKT's campaigns aim to encourage people to discuss organ donation and to join the NHS Organ Donor Register, to raise awareness of the success of transplantation and the shortage of donated organs and to increase the number of opportunities and ease with which people can join the register. Primary audiences are 'public' and 'NHS/health professionals' which break down into targeted segments, eg existing and potential donors, young people (16-25yrs) motorists, BME groups, charities, and others.

Partnerships are a key element of UKT's marketing/campaigning. UKT has ensured the development of links with a broad range of public and private sector organisations, and other individuals and volunteers to help improve access to information/leaflets, and to promote signing up to the organ donor register

In addition to partnerships UKT uses a variety of marketing communications to disseminate information about organ donation and facilitate registration. Door drop campaigns, radio advertising, cinema advertising, poster advertising (buses and general hoardings) and printed advertising in special interest/trade magazines such as nursing, cinema, BME has been carried out. UKT has also produced a range of promotional leaflets which are distributed to GP's surgeries and libraries and available free of charge to the general public, businesses and interest groups for their own promotions. UKT also places articles in the media, especially at the regional newspapers. Online publicity materials are also available to individuals, charities and businesses to raise awareness and encourage registration.

An Education Pack targeted at 14-16 year olds has been developed to encourage teachers and pupils to learn about organ donation (and blood, tissue and bone marrow donation) as part of the school curriculum.

UKT also exhibits at events such as Freshers' fairs, Asian festivals (melas) or Intensive Care Society meetings, which help to reach the key audiences.

1.3. Information and Education on organ donation and transplantation

Initiatives of variable nature have been developed within all ALLIANCE-O countries in order to efficiently inform and educate the general population on organ donation and transplantation.

Information is available by different means in all the countries, as outlined in table 1. Free informative brochures are available in most of ALLIANCE-O countries. However, the presence of a 24 hour telephone available for general information is only available at 4 of the seven countries. While general information is also available at the national (and even regional) transplant organizations web site, the possibilities of questions and answers through the web is a possibility to be explored in several of our countries, although most of the organizations have developed other tools/mechanisms to efficiently answering questions raised by the public (e.g a public relations department). On the other hand, specific talks on donation and transplantation are conducted by all the national transplant agencies mostly upon request.

Specific actions have been also taken at several of our countries which are targeted to inform students/teenagers/young adults on organ donation and transplantation (table 1). In France, ABM has even developed one specific web site for this segment of the population. Even more, efforts to train teachers as possible vias to disseminate information to students/teenagers have been performed in several ALLIANCE-O countries.

Table 1: Informative activities targeted to the general population among ALLIANCE-O countries.

	FRANCE ABM	GERMANY DSO	HUNGARY HT	ITALY CNT	PORTUGAL OPT	SPAIN ONT	U.K UKT
Free informative brochures	X	X	X	X		X	X
Telephone 24 hours for general information	X	X		X		X	X
An informative web presence	X	X	X	X	X	X	X
Questions/answers on the web page	Improving	X				X	X
Questions/answers through other mechanisms	X	X	X	X		X	X
Informative meetings at schools				X	X	X*	
Informative material for teenagers	X**						X
Material to be used by teachers	X***	X***				X***	X

**Organized by regional transplant offices in specific regions within the country*

*** ABM has developed an informative DVD for teenagers*

**** ABM and ONT have developed a book to inform teachers on organ donation and transplantation. DSO has available on its homepage material especially designed to teachers to be used in biology or ethics class*

1.4.Tools to register the will on organ donation: donor and non donors registries and donor card

An organ donor's registry is available in Hungary, Italy and United Kingdom. In Portugal (RENDA, created in 1994) and France, a non donor's registry has been developed. Outstandingly, the donor card is available at all countries within ALLIANCE-O.

2. Promotional and educational activities targeted to specific groups in the society

This section describes those promotional activities performed within ALLIANCE-O countries which have been targeted to specific groups within the society. In

particular, information is provided for promotional actions and activities targeted to the mass media, the magistrates and the minorities.

2.1. Mass Media

Mass media is considered a very specific target of the population that deserves special attention. Mass media may support publicity campaigns activated by the transplant organizations or other institutions in charge of promotion of organ donation and transplantation, but the reason why they represent a special target in promotion of organ donation is because mass media actively generate and spread information and news on organ donation and transplantation. This section describes those actions aiming to ensure positive and accurate information of the mass media when disseminating information on this issue and to manage negative news spread by the media.

2.1.1. France

ABM has a constant relation with the mass media. Information on donation and transplantation issues is provided to the mass media mainly upon request. Press office services are considered as a priority all year long.

Specific actions with the mass media have been developed during the informative campaigns. Press articles are analyzed after each campaign.

2.1.2. Germany

DSO has a public relations department that ensures press releases on homepage and via a distributor and press service on homepage. The public relations department supports all kinds of activities in the mass media (radio, television and press) upon request. For example, a "doku-soap" on Arte; or the organ donation week on the public TV Channel (ZDF) were supported by the DSO. For the national Donation day (2004 and 2005) a radio kit was designed (approx. 1:30 min. with interview and information on donation) and offered to a large number of Radio stations to play during the day.

2.1.3. Italy

Specific contact with mass media has been performed to support specific campaigns. However, CNT usually provides information on donation and transplantation to the mass media upon request.

2.1.4. Spain

In Spain, ONT has ensured a fluent and constant relation with the mass media has been ensured in the last years. The 24-h transplantation hot-line previously described has been established as one single telephone number for the entire country yielding instant access to the ONT to anyone, including the media. This simple measure ensures that the media may have rapid, accurate and reliable information at any time. Even more, a space for the mass media has been created at ONT website. Therefore, close attention to the media is paid at any time upon request.

ONT ensures press releases periodically on the basis of regular successes achieved in the field of organ donation and transplantation.

On an annual basis, periodic meetings of journalists, experts in communication and opinion leaders in the field of transplantation are being developed. The aim of these meetings is to influence and educate the media in issues related to transplantation, openly addressing misconceptions and emphasizing and highlighting the positive life-saving aspects of organ donation and transplantation. Relation with the mass media is cultivated and facilitated also through this kind of meetings.

An active analysis of news on organ donation and transplantation released on the mass media is routinely performed. This analysis favours a rapid reaction in cases of negative information released by the media.

2.1.5. United Kingdom

UKT issues planned, written news releases to national and regional press, radio and TV media. They are all published on UK Transplant's public website -

http://www.uktransplant.org.uk/ukt/newsroom/news_releases/news_releases.jsp

Much of this material supports ongoing awareness campaigns run by UKT to ensure as much of the target audience as possible hears about the key messages.

UKT also provides a 24 h press office service, answering journalists' enquiries and offering additional information, such as statistics and statements to help ensure media coverage is well-informed.

Although statistically there is no evidence to show that increased media coverage of donation and transplantation results in more actual transplants, high-profile coverage of particular issues can generate considerable public response in terms of prompting people to join the Organ Donor Register.

2.2. Magistrates

Refusals to donate due to magistrate and coroner's refusal may represent also an obstacle in the process of donation. Some of the partners within ALLIANCE-O have developed actions targeted to this specific group to ensure that judicial refusals to donate are reduced to a minimum.

For instance, in Germany, the seven DSO regions organize regional meetings with state procurators, pathologists and coroners on an irregular basis, in order to inform them about organ donation. This same kind of meetings is annually developed by the ONT in Spain.

2.3. Minorities

Minorities have been classically considered as more reluctant to donate, according to general and specific surveys conducted at different countries and published in the literature. Therefore, they represent a group to whom specific actions and activities have been performed within some ALLIANCE-O countries, especially in France and United Kingdom.

2.3.1. France

At the end of the year 2004, a symposium entitled "Monotheist religions and organ transplantations" was organized with catholic, Jewish and Muslim's representatives, to provide information on their opinion on organ donation.

Recently, ABM interviewed this same religion's representatives to give their position for a new DVD.

A working group in charge of defining the reasons to refuse organ donation among different ethnic groups has been established. The group aims to construct some guides on the issues to help the transplant coordinators in the family interview.

Finally a course on bereavement, rites and community is held on an annual basis.

2.3.2. Germany

Donor cards are available in 10 languages on the homepage. Some brochures have been translated into Turkish.

2.3.3. Italy

Workshops and seminars with representatives of religious groups and minorities are usually performed during promotional campaigns, to provide information on their opinion on donation/transplantation and the way their beliefs may represent a barrier to organ donation.

2.3.4. Spain

A survey targeted to immigrants is to be performed in Spain by the ONT. The same items which have been studied in the context of the survey targeted to the general population will be reproduced in this survey. Besides, specific new items will be added to the questionnaire. The aim of this survey is to address the degree of information on donation and transplantation, sources from which information is obtained, opinion on the way it would be desired to receive such information, attitude toward donation of own organs and organs of a deceased close family member, opinion on the procedures used to ask for consent to donate, discussion of organ donation within the family circle, opinion on the organ donor card and other tools to express the wishes on organ donation and other issues. Besides, a deep evaluation of the reasons to support or not support organ donation is intended to be performed. This survey will help to develop specific actions targeted to this specific group of opinion.

A symposium entitled "Donation without borders", where representatives of religious groups and minorities were invited to provide information on their opinion

on donation/transplantation and the way their beliefs may represent a barrier to donation was developed at the end of 2006 by the ONT. This was the first action developed in Spain specifically targeted to this group of opinion and which led to a global strategy to address refusals to donate in this group. A workshop is under preparation in the next months which will be attended by transplant coordinators and social/cultural mediators to interchange opinions and information on donation and transplantation.

ONT is preparing specific leaflets targeted to minorities.

2.3.5. United Kingdom

UKT has conducted specific studies focused on BME groups, since they are more reluctant to donation. In particular, in February 2006, a research was carried out with Black Caribbean and South Asian ethnic groups to evaluate their awareness and attitudes towards joining the organ donor register.

Specific promotional campaigns targeting BME groups have been developed by UKT. For instance, in the year 2003, as part of an initiative to explore religious perspectives on organ donation, UKT researched and produced a series of leaflets, working closely with religious leaders of Buddhism, Christianity, Hinduism, Islam, Judaism and Sikhism. A national conference for hospital chaplains was organised in September 2003 and a summary leaflet followed on from this in 2004. Funding for the project has now ended, but the work has laid the foundations for widening discussion and education with the diverse religious communities of the UK. These leaflets can be found on UKT's website at:

http://www.uktransplant.org.uk/ukt/how_to_become_a_donor/religious_perspectives/religious_perspectives.jsp

UKT also works with BME media and community partners to disseminate information to the all BME groups using relevant terminology and spokespeople. Support from black and South Asian celebrities has also helped raise awareness within BME groups.

3. Promotional activities targeted to health-care professionals

This section describes promotional activities performed among ALLIANCE-O countries which are targeted to health-care professionals, whether involved or not

in the process of donation and transplantation. Health-care workers are involved in the identification and referral of potential donors, the family approach and the dissemination of information on donation and transplantation to the public, which has led the different transplant organizations to the development of specific studies and actions targeted to this group.

3.1. Surveys to health-care professionals

3.1.1. France

A survey aiming to analyze the perceptions of health-care professionals, linked or not to the process of organ donation is actually running in France. Results will be available in December 2007.

3.1.2. Germany

The BZGA conveyed a survey in 2004 to find out whether general practitioners could serve as "multipliers" for informing the population about organ donation.

3.1.3. Portugal

In the year 2003 a survey to evaluate the opinion on organ donation and transplantation among health-care workers was conducted at three hospitals of Lisbon area. Results of this survey made very apparent the need to organize courses on donation and transplantation targeted to health-care professionals.

3.1.4. Spain

A specific survey was conducted along the year 2006 to health-care professionals not directly involved in the process of donation. In particular, the survey was performed among general and emergency practitioners. The aim of this survey was to evaluate the attitude of these professionals towards donation and transplantation, their knowledge about the Spanish transplant procurement network, the figure of the transplant coordinator and the whole process of organ donation, the information they provide to the public on organ donation and their attitude towards their active cooperation in the process. Results of this survey led to the conclusion that this group of health-care professionals has a positive attitude towards organ donation, although they perceive their need on specific information

and training on the issue. In general terms, they have a positive attitude towards an active cooperation in the donation process.

This survey will guide specifically tailored actions targeted to this group of health-care professionals, in order to ensure their information and training on the subject, so they can effectively disseminate information on organ donation to the public and they can actively participate in the process (in the case of emergency care practitioners).

3.1.5. United Kingdom

UKT consistently promotes messages to NHS audiences. Health-care professionals have been surveyed for their views on organ donation. In particular, UKT conducted a market research in December 2004 with NHS to gauge the attitudes of health service workers to organ donation.

3.2. Informative activities to health-care professionals

3.2.1. France

Since 2004, ABM has a specific program targeted to health-care professionals who are not involved in the process of organ donation put in place. These programmes aim to encourage these professionals to identify potential donors in their hospitals and then to transfer them to a place where organ removal can be carried out, after the corresponding interview with the family of the deceased.

3.2.2. Germany

DSO regularly organizes training programmes targeted to health-care professionals on donation and transplantation

3.2.3. Italy

Regional and inter-regional coordination centres have usually in charge the organization of seminars, workshops and courses in their areas to the education of health-care professionals. Besides, regular training programmes for health-care staff at a national and regional level are organized or promoted by CNT.

3.2.4. Portugal

In the annual meeting of the ICU society a round table to discuss on organ donation and transplantation is held.

3.2.5. United Kingdom

UKT regularly organizes training programmes targeted to health-care professionals on donation and transplantation.

3.3. The family approach

As stated in D 2.1 (State of the art in expanding the donor pool), several technical and training initiatives have been carried out among almost all ALLIANCE-O partners in order to improve the technique of the family approach in general terms and to specifically address the issue of organ donation.

As described in table 2, the issue of the family approach has been developed through specific local courses or in the context of international programmes, as EDHEP or TPM courses. These courses have been targeted not only to health-care professionals directly involved in the process of donation, but also to other health-care professionals.

A guideline on the family approach has been produced or is under development in some of the ALLIANCE-O countries.

Finally, an active analysis of family interviews in the context of organ donation has been carried out only in some of the participating countries, at a national or a regional level. The aim has been to analyze what were the reasons to refuse or accept organ donation by a specific family, to analyze specific circumstances in the interview that could have influenced the decision and to identify those refusals potentially reversible, through a critical analysis of the interview.

Table 2: Technical and training initiatives focused on the family approach.

	FRANCE ABM	GERMANY DSO	HUNGARY HT	ITALY CNT	PORTUGAL OPT	SPAIN ONT	U.K UKT
Transplant Procurement courses	X	X	X	X	X*	X	X
EDHEP	X**	X				X**	
Other local courses/workshop on the family approach	X	X		X		X	X
Questions/answers on the web page	Improving	X				X	X
Guidelines on the family approach	Improving					Improving	
Analysis of interviews requesting organ donation	X***	X****		X*****		X***	X

*In 2001, OPT in collaboration with Fundació Boch I Gimpera (Barcelona University) organized a TPM course, targeted to health-care professionals linked to the harvesting of organs, specifically to ICU workers.

**Modified EDHEP: seminars focused on the communication of bad news

*** In some regions within the country

**** Several publications produced: 1) Decision Process of Relatives with Respect to Organ Donation after Sudden Death; 2) Experiences of relatives in hospital after the sudden death of a loved one; 3) Communication with relatives of sudden death patient and request for organ donation –results from the doctors perspective; 4) Herr Dr. Wesslau Ihre fehlt mir noch (die von 1992). Also the DSO- Region Mitte (central) has started a project in order to evaluate the experiences of donor families during the procurement process.

***** Information is published in Italian in the CNT web site at the page:

<http://www.trapianti.ministerosalute.it/cnt/cntArchivioRelazioni.jsp?area=cnt-generale&menu=menuPrincipale&label=datdoc>

V. POSITION OF THE GROUP ON PROMOTION OF ORGAN DONATION

Organ transplantation has the undeniable characteristic that it represents a therapy which needs the contribution and active participation of the society in the donation process. Therefore, increasing awareness of the need of organ donation among the citizens has been classically considered as crucial in order to ensure high organ donation rates and low rates of refusals to donate. Promotion of organ donation is one of the duties of transplant organizations and a set of different actions and activities of very variable nature have been or are under development in the European countries, as described in the previous section.

The consortium has reviewed and discussed their position on promotion of organ donation, in general terms and on specific initiatives, which is summarized below:

a) The main objectives of promotion of organ donation and transplantation are **increasing referral of brain deaths** to be considered as potential organ donors and **decreasing refusals to donate**.

b) Surveys targeted to the general population and/or specific groups in the population to explore a set of issues on the field of organ donation and transplantation have been performed at an international and a national level. These surveys have been focused on the analysis of the level of information on donation and transplantation of the general population and/or specific groups, sources from which information is obtained, opinion on the way it would be desired to receive such information, attitude toward donation of own organs and organs of a deceased close family member, opinion on the running procedures applied to ask for consent to donate, discussion of organ donation within the family circle, opinion on the organ donor card and other tools to express the wishes on organ donation during lifetime and other issues. Even more, surveys may help to evaluate the profile of persons prone or not prone to donate, as well as reasons that justify their individual attitudes. **Although surveys may not be considered themselves as promotional activities, the collected information may guide the design of specific promotional actions and activities and may provide useful tools to develop an improved technique on the family approach and the request for organ donation.**

c) Students, teenagers and young adults represent a segment of the population which has been the target of specific surveys and promotional activities among ALLIANCE-O countries. Working with this specific segment of the general population is based on the reiterative observation that they are usually more favourable to organ donation than other age segments of the population (7) and that they may facilitate the development of conversations on the issue of organ donation within the family context. **The development of specifically tailored efficient educational and informative tools targeting this group should be encouraged.**

d) Minorities, religious and ethnic groups have been recognized in general terms as more reluctant to organ donation. This observation has led to several transplant organizations to develop specific promotional activities targeted to these groups, on the basis of previous studies evaluating the obstacles to

support organ donation these specific groups may have. **Based on local circumstances and needs, the development of specific informative tools targeting these groups could be considered.**

e) Direct publicity campaigns on donation and transplantation are not expected to have a deep impact on the donation rates. Apart from some anecdotal observations, there is no evidence in the literature documenting that this kind of actions are really able to positively influence the attitude of the public towards organ donation. On the contrary, there is a growing feeling that their practical effects are close to nil (8, 9). There are many reasons that may explain the lack of proven success of publicity campaigns on the attitudes of the population towards donation and subsequently on the rates of organ donation. The need of an important investment to ensure a deep impact of the message on the public opinion is possibly one of the most important obstacles. Great investments in direct publicity campaigns, especially on television, the favourite media of the population, are out of the possibilities of transplant organizations and those authorities in charge of promotion of organ donation. Other reasons have been appointed in the literature, as the institutional character of the campaigns as responsible of a lack of effect and the contents of the messages when promoting organ donation (10): these messages direct or indirectly include the concept of the death of the individual, a *taboo* issue in our modern society.

However, efficient information on donation and transplantation should be easily available at any time to ensure the society and specific groups inside the society are aware of the efficiency of transplantation and the need for organ donation. For countries where donors and non donors registries are available, it should always be ensured that any registered decision on donation of own organs is made on the basis of full and accurate information.

f) Donor cards are widely used among the countries and they may indeed facilitate the communication with the family at a moment of grief. However, it should be outlined that in countries with presumed consent, donor card should not be an official document.

g) The scientific community has sometimes underestimated the power and influence of the mass media, both in a positive or a negative sense. Recent examples show that conflictive news on organ donation may activate a cascade of comments, discussions and debates, with potentially worrisome effects on the donation rates (11). Even more, the deep impact of negative and positive news on

organ donation and transplantation is very well illustrated, and examples are available in many countries. It is obvious that adverse publicity causes enormous damage to altruistic organ donation all over the world. In this context, **the mass media may be considered a very specific target of the population that deserves special attention**, when considering the issue of promotion of organ donation. Besides, the mass media represent the most adequate channel to reach the public opinion. **A constant, fluent and easy relationship of the transplant organizations with the mass media should be ensured and cultivated.** Managing adverse publicity must be combined with adequate and systematic spread (via the media to the medical and lay community) of the positive and life-enhancing aspects of organ donation and transplantation. Also, periodic meetings of journalists, experts in communication and opinion leaders in transplantation could represent a pragmatic approach to influence and educate the media in issues related to transplantation. Misconceptions must be addressed openly, at the same time emphasizing and highlighting the positive life-saving aspects of organ donation and transplantation.

h) Health-care professionals, whether directly involved or not involved in the process of organ donation must be aware of the fact that it is necessary to stick a reliable and homogeneous system of information on organ donation and transplantation in which the public can have full confidence. Health-care professionals, as responsible for identifying potential donors, approaching the grieving families and/or providing general information on the process of organ donation and transplantation **deserve a special support to ensure that a positive climate on organ donation is created inside the society.**

i) Promotion has been classically considered as crucial in order to ensure high donation rates. Similarly, low donation rates have been frequently explained by the "lack of awareness" of the general population. Apart from transferring the problem to a comfortable fatalism, this concept should be at least questioned on the basis of simple observations. The recently disseminated results derived from a European survey exploring the attitudes of the citizens towards organ donation, reflected some incoherencies between the attitudes of the population and the rate of organ donors at several countries (5). This means that those countries with a better attitude towards donation were not necessarily the ones with higher organ donation rates. **This observation should let us conclude that promotion of organ donation is something which is needed, but that it is not enough to ensure the success of the organ procurement and transplantation system.**

To efficiently decrease refusals to donate, **promotion itself should be complemented by the specific training of those professionals involved in the process of donation and transplantation. Training on the technique of the family approach should be highly stimulated and supported.** In the context of a positive climate towards donation and transplantation, an adequate technique in the family interview to request organ donation can make a major difference on obtaining a positive or a negative answer to proceed with organ donation.

j) Promotional activities, integrated with a specific training program for those health-care professionals involved in the process of donation and transplantation, should be put in place as a national strategic plan. The informative and educational needs of the general population, specific groups and health-care professionals, whatever involved or not in the process of donation should be explored. A clear definition of objectives to be reached within this global strategy should be established. Specifically tailored promotional, educational and training activities should be accordingly developed. A general consensus of all those involved in the process of organ donation and transplantation is essential to transmit a clear, consistent and uniform information to generate a positive climate on donation and transplantation, not only at a national, but also at a European and even a global level.

VI. REFERENCES

1. Matesanz R, Miranda B. Expanding the organ donor pool. The Spanish Model. *Kidney Int* 2001; 59: 801-803.
2. International figures on organ donation and transplantation-2006. Newsletter *Transplant* 2007; 12 (1): 34. Spanish National Transplant Organisation website. Available at www.ont.es. Accessed August 27, 2007.
3. 1999-2005 data of the Quality Assurance Programme. Spanish National Transplant Organisation website. Available at http://www.ont.es/.contenido.jsp?id_nodo=271&&keyword=&auditoria=F. Accessed August 27, 2007.
4. Siminoff LA, Gordon N, Hewlett J and Arnold RM. Factors influencing families' consent for donation of solid organs for transplantation. *JAMA* 2001; 286: 71-77.
5. Special Eurobarometer: Europeans and organ donation. European Commission website. Available at: http://ec.europa.eu/public_opinion/index_en.htm . Accessed August 31, 2007.
6. Dominguez-Gil B, Miranda B, López JS, et al. Decrease in refusals to donate in spite of a lack of change in the attitude of the general population towards organ donation: a call to review the factors influencing refusals. Accepted for presentation at the 15th European Transplant Coordinators Organization Congress. Prague, Czech Republic, September 28, 2007-October 3, 2007.
7. Boulware LE, Ratner LE, Sosa JA, Cooper LA, LaVeist TA, Powe NR. Determinants of willingness to donate living related and cadaveric organs: identifying opportunities for intervention. *Transplantation* 2002;73 (10):1683-1691.
8. Cuzin, B, Dubernard, JM. The media and organ shortage. In *Organ Shortage: The Solutions*. Ed by JL Touraine et al, Kluwer Academic Publisher, Dordrecht, 1995, pg 287.
9. Frates J, Bohrer GG, Thomas D. Promoting organ donation to Hispanics: the role of the media and medicine. *J Health Commun* 2006;11(7): 683-698.
10. Matesanz R. Transplantation and the mass media. *Organ Donation for Transplantation. The Spanish Model*. Ed by Grupo Aula Médica, S.A., Madrid 1996, pg 111.
11. Kerr C. Hoax raises awareness about organ shortages. *CMAJ* 2007; 177(2):135.