



# **COMMUNICATING ABOUT ORGAN DONATION AND TRANSPLANTATION**

A handbook on theoretical  
and practical aspects



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Co-funded by  
the Health Programme  
of the European Union

“Communicating about organ donation and transplantation – A handbook on theoretical and practical aspects”

*This handbook is a product of FOEDUS Joint Action, co-funded by the Health Programme of the European Union.*

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## LIST OF ABBREVIATIONS

ACTOR	A study funded in 2012 under the EU Health Programme to map the uptake of the EU Action Plan on Organ Donation and Transplantation (2009-2015) in EU Member States
COORENOR	Coordinating an European Initiative among National Organisations for Organ Transplantation (EU-funded project)
EC	European Commission
EDD	European Donation Days (EU-funded project)
EU	European Union
FGD	Focus group discussion
FOEDUS	Facilitating Exchange of Organs Donated in EU Member States (EU-funded project)
JA	Joint Action (type of grant funded under the EU Health Programme)
NCA	National Competent Authority Directive 2010/53/EU on standards of quality and safety of human organs intended for transplantation defines a “competent authority” as “an authority, body, organisation and/or institution responsible for implementing the requirements of this Directive”
SCT	Social cognitive theory
WP	Work Package of EU-funded projects

## I. EXECUTIVE SUMMARY

### Background to the project and purpose

Transplantation medicine has become an established procedure for patients with end-stage organ failure. The results of transplantation have improved substantially over the years, providing transplanted patients with the prospect of a longer life with quality. At the same time, organ shortage is the most serious factor limiting this treatment. In addition, not every patient within the European Union currently has access to this often life-saving treatment. In order to overcome these obstacles, various actions are being undertaken to ensure the optimal allocation and use of organs donated for transplantation. In this regard, the cross-border exchange of organs donated for transplantation is considered to be particularly important.

FOEDUS (Facilitating Exchange of Organs Donated in EU Member States) was a Joint Action co-funded by the European Union under its EU Health Programme (2008–2013). The project aimed to improve the practice of cross-border organ exchanges within the European Union as prescribed in Directive 2010/53/EU on standards of quality and safety of human organs intended for transplantation and in the Action Plan on Organ Donation and Transplantation (2009-2015): Strengthened Cooperation between EU Member States created by the European Commission. Comprising seven work packages, 18 national competent authorities (NCAs) participated in the project that was led by the Italian Centro Nazionale Trapianti (CNT).

### Presentation of the work package

The present handbook is the final deliverable of FOEDUS work package 7 on communication and public awareness. The work package, which involved 12 partners and was led by Deutsche Stiftung Organtransplantation (DSO) and Slovenija Transplant (ST), focused on communication in organ donation and transplantation, referring to general information as well as specific information on cross-border organ exchanges and crisis communication.

### Structure of the handbook

The handbook “Communicating about organ donation and transplantation – A handbook on theoretical and practical aspects” provides an extensive overview of communication in the field of organ donation and transplantation. Corresponding to the course of the project, it is divided into various sections covering different aspects, such as theoretical foundations and practical applications. In this manner, WP 7 offers several starting points that might be useful when developing or revising a communication strategy.

## **Part I – Theoretical approach to communication**

Social marketing is understood as the application of marketing principles and techniques in order to influence people's attitudes and behaviours. It tries to convince a target group by appealing to its principles and rationality. Therefore, it implies knowledge from many disciplines, including sociology and psychology. Part I of the handbook presents the underlying theories and practical techniques of social marketing.

## **Part II – Communication – analysis of studies**

Results of an analysis of studies dealing with the effectiveness of certain communication measures are presented in Part II. The analysis represents one milestone within the project. It was conducted in order to obtain an overview of the current state of the art in evaluating campaigns as well as to acquire some advice on how to communicate effectively about organ donation and cross-border organ exchange.

## **Part III – Communication – perspective of stakeholders**

Part III of the handbook starts by presenting the original as well as an extended communication model. This serves to both provide awareness of the growing complexity of communication, which is also caused by the development of new and social media, and introduce the main participants of every communication model, namely the sender and the receiver. In this handbook, the sender is represented by the NCAs. In order to provide an insight into their experiences, needs and wants, the results of a survey carried out among FOE-DUS partners at the beginning of the action are presented. The survey's objective was to analyse the partners' experiences along with their needs and wants.

The receiver is represented by an important multiplier, the media. Here, a report on the 4th journalist workshop on organ donation and transplantation organised by the European Commission is presented as well as three reports from a Greek, a Slovenian and a German journalist.

## **PART IV – Development of messages**

This practical section of the handbook describes a structured process for how to develop messages for communication purposes. In connection with the development of this process, two expert workshops were conducted. These workshops were attended by representatives of the NCAs as well as external medical and communication experts. Using this approach, two important aspects were fulfilled. On one hand, it permitted the involvement of different relevant disciplines. On the other hand, it ensured a coordinated operation at the European level. A jointly developed communication concept along these lines did not previously exist.

## **PART V – Messages – Test of effectiveness**

A way to evaluate the effectiveness of communicational measures and/or messages is provided by presenting the results of a test of effectiveness. The general aim of the test was to explore how the public perceived a set of developed messages and how they reacted to them in terms of cognitive and emotional response. Selected messages contained clear and comprehensible information about organ donation related to organisational, medical and cross-border exchange aspects. Another aim of this test was to draw valid conclusions and prepare recommendations for the NCAs' communication strategies with the media.

## **PART V – Crisis communication**

The handbook concludes with a practical introduction to crisis communication. This topic was included according to the explicit wish of the WP 7 members. The chapter describes the role and contribution of crisis communication, especially focusing on communication with the media. By using practical examples and checklists, this chapter aims to help professionals in organ donation and transplantation prepare for and take proper action when confronted with possible crises.

## **Concluding remarks**

The present handbook offers a comprehensive overview of communication in the field of organ donation and transplantation. It aims to provide assistance to NCAs for developing or revising communication strategies. By including specific aspects such as cross-border organ exchange or crisis communication, this handbook intends to provide topical information to communications officers and/or departments.



## II. FOREWORDS

More than 100 countries in the world now have organ transplant services. Successful programs of organ donation and transplantation within each of these countries require the support and interaction of three important stakeholders: the government (representing society through its ministry of health), the professionals who perform the transplants, and the media that validate the need for organs and testify independently to the benefit of transplantation.

The ministry of health oversees the practice of donation and transplantation because it is a societal event beyond the limit of medical practice – the source of organs for transplantation is derived from the living and from deceased members of the society. For the living donor, there must be the assurance of safety; for the deceased, there must be the assurance of an equitable distribution of organs. Professionals have responsibility to communicate with the ministry by registry reports of activity and to be transparent with the media to enable a societal trust. The media must bring a public awareness for the need of organs but also the benefit of transplantation as the compelling reason for members of society to donate.

Communication among the stakeholders is essential to establish and sustain successful organ transplant programs. Such communication serves the priority interest of patients with the regular (mandated) interaction through national registry reports. The interest of all stakeholders is served when there is a request by the public for specific information regarding organ donation or transplantation.

Thus, this handbook entitled “Communicating about Organ Donation and Transplantation” is a timely and comprehensive document derived from the FOEDUS Project (Facilitating Exchange of Organs Donated in EU Member States) funded by the European Commission. The editors display their expertise in communication by assembling a compendium of theoretical, academic and practical aspects of communication specifically in the field of organ donation and transplantation. It describes various approaches to communication among (and from) the stakeholders and it suggests innovative procedures to develop the communication message.

The audience of this handbook will especially be the transplant professionals – exposing them to the science of communication but it is also targeted to media professionals by describing specific facts and circumstances in the field of organ donation and transplantation.

The handbook offers as an effective step-by-step introduction to the theoretical background (Part I). The reader will find dissertations on Maslow’s Needs and Bandura’s Social Cognitive Theory, selected by the Editors as relevant models to explain the theoretical framework of social marketing.

A review of published literature on campaigning and in the field of organ donation and transplantation is presented in Part II. Little has been written on this topic previously and this section validates the need for such a handbook.

A more practical contribution comes with PART III with a perspective given regarding the experience with media communication and the perceived impact of media coverage. An assessment by three media representatives regarding the structure of cooperation between the media and professionals is helpful.

Specific communication measures are provided in PART IV, where a structured process is described on how to develop messages for communication purposes. The process was established within two workshops that were held within the course of the project especially pertinent for participating European member states. Nevertheless, a reader from outside the EU may still find the divergence of the presentations informative.

Part V presents test communication messages. The objectives are clearly presented with chosen methodology of qualitative testing. The handbook finishes with PART VI on Crisis communication again with practical recommendations for communication experts to prepare for what otherwise might be a crisis in transparency and trust.

Thus, in total, “Communicating about Organ Donation and Transplantation” is a gallant and important contribution to the field of organ donation and transplantation for the stakeholders. It is a remarkable interdisciplinary asset for such diverse but connected group – connected to serve a unique and needy population of transplant patients.

*Francis L. Delmonico, M.D.  
Professor of Surgery Harvard Medical School  
Massachusetts General Hospital  
Chief Medical Officer  
New England Organ Bank  
United States of America*

Firstly, I would like to congratulate all partners of FOEDUS WP7 and especially the work package leaders for the successful realisation of this truly European project. As a member of the FOEDUS External Advisory Board, I had the opportunity to read this document in the last months of 2015, shortly before its publication.

This handbook provided many new and surprising insights, which accordingly determine the overall evaluation. It is a well-structured work on communication in donation and transplantation, providing different approaches. Depending on particular aims and the target public, the handbook imparts different perspectives on communication, taking into account studies carried out in different countries with different realities. The distinct chapters are very appropriate for dealing with this topic. Though risky, the authors have succeeded to include subjects such the definition of death, waiting lists, ethical and religion aspects, lack of transparency or traffic of organs. Furthermore, the important aspects of crisis communication are included together with practical recommendations.

I confirm that some of the conclusions are totally in agreement with the Spanish model since campaigns do not affect or at least are not directly connected to increases in organ donation. Further, I would like to emphasise that the training of health-care professionals and journalists is pivotal with regard to their influence population in terms of the culture of donation.

This handbook is a very valuable contribution in connection with the ongoing development of organ donation and transplantation in the European Union.

*Rafael Matesanz  
Director of ONT (Organizaci3n Nacional de Trasplantes)  
Ministry of Health, Social Services & Equity  
Spain*

### III. PREFACE

Communication activities on organ donation and transplantation are an essential part of the daily operations of national competent authorities (NCAs). Although regularly performed, there is no generally applicable way to ensure effective communication on this sensitive topic. Moreover, there is no evidence supporting the effectiveness of communication measures like, for instance, campaigns. Thorough knowledge is missing regarding how measurable effects can be created.

Fortunately, the NCAs are not left alone with this challenging task. The European Commission is actively engaged in backing communication activities on organ donation by publishing several comprehensive documents like the “Action Plan on Organ Donation and Transplantation (2009–2015)”, or supporting events like the “European Organ Donation Day” or dedicated projects.

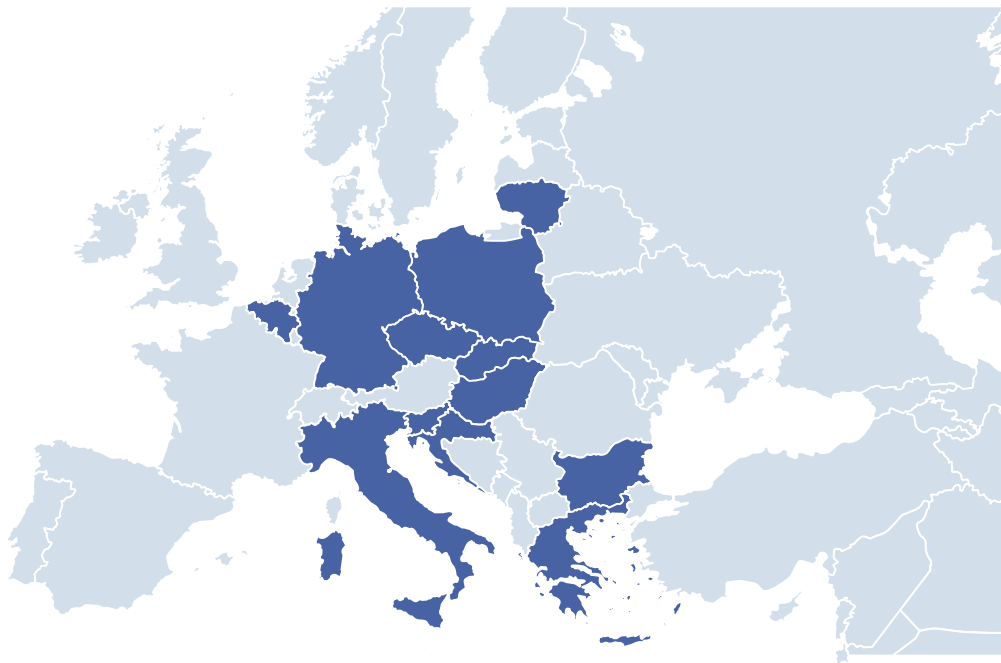
This handbook was developed within work package 7 of the FOEDUS Joint Action cofunded by the European Commission. It is a comprehensive product that serves a dual purpose. First, it aims to provide practical guidance to NCAs for their daily communication with the media and the public. Second, it also contains relevant theoretical aspects to gain a deeper understanding of communication processes. In order to provide short and useful information to the reader, every chapter is complemented with an overview of its contents and key points. Specific attention was paid to the development of messages on organ donation and transplantation, which were later tested for their effectiveness on samples representing the general public. The performed qualitative study highlighted new and valuable information related to the presentation of messages aiming to raise awareness, support the decision-making process and avoid a loss of confidence and trust. This handbook has been given added value by the contributions of several external authors. We would like to thank Tanja Kamin and Juliette van der Laan for their chapters on social marketing and crisis communication. Further, we would like to thank the journalists Diana Zajec, Marina Zoe Saoulidou and Felicitas Witte for sharing their views on cooperation between NCAs and the media.

The development of this handbook offered a special experience to all the contributors because this is the first project on communication elaborated for and by the NCAs. We would like to thank the European Commission, especially H el ene Le Borgne, and the project coordinators at CNT for their support during all phases of the project. We strongly believe this handbook will find its place at the NCAs, ministries of health, transplant and procurement centres and other competent institutions in European countries or even beyond. FOEDUS WP 7 was the first work package to have been led by two countries, Germany and Slovenia. This co-leadership has been perceived as very constructive and beneficial. It is another positive accomplishment of this European project.

Danica Avsec and Thomas Breidenbach

#### IV. ACKNOWLEDGEMENT

Work package 7 of FOEDUS JA involves 12 partners (see Figure 1) which voluntarily applied to participate in this WP on this topic. Each partner is an associated partner of FOEDUS.



*Figure 1: FOEDUS WP 7 participating partners for work package 7*

The two WP leaders, the German Deutsche Stiftung Organtransplantation (DSO) and Slovenija-Transplant (ST), would like to take the opportunity to thank all the partners for their cooperation. The associated partners of work package 7 are:

- Bulgarian Executive Agency for Transplantation (BEAT), Bulgaria
- Ministry of Health of the Republic of Croatia (MoHRC), Croatia
- Czech Transplantation Coordinating Centre (KST), Czech Republic
- Hellenic Transplant Organisation (EOM), Greece
- Hungarian National Blood Transfusion Service (OVSZ), Hungary
- National Institute of Health / Italian National Transplant Centre (ISS-CNT), Italy
- National Transplant Bureau (NTB) under the Ministry of Health, Lithuania
- Polish Transplant Coordinating Center (POLTRANSPLANT), Poland
- National Transplant Organisation (NTO), Slovakia
- Federal public service Ministry of Health Belgium (PFS PH), Belgium

We would also like to thank our external partners for their valuable contributions to this handbook :

- Ipsos Global Market Research Company
- Tanja Kamin, Assistant Professor, Department of Media and Communication Studies, University of Ljubljana, Slovenia
- Juliette van der Laan, Manager Communication, Eurotransplant International Foundation, the Netherlands
- Marina Zoe Saoulidou, Journalist, Greece
- Felicitas Witte, Journalist, Germany
- Diana Zajec, Journalist, Slovenia



# I INTRODUCTION

The following chapter is a general introduction. It provides descriptions of:

- the present handbook as part of the FOEDUS Joint Action and a definition of its target group;
- the current situation for organ donation and transplantation in Europe;
- FOEDUS as part of EUROPE 2020 as well as the structure of the JA; and
- WP7 and its development.

Transplantation medicine has become an established therapy for patients with end-stage organ failure. The results of transplantation have improved substantially over the years, providing transplanted patients with the prospect of a longer life with quality. Although carried out in all European countries, there are differences regarding the availability of transplant programmes. While some countries offer transplant programmes for every organ and patient group, others do not. To offer their citizens access to treatments that might not be available within their own national systems, some countries have developed and are still building cooperation; for example, bilaterally between two countries/authorities, or multilaterally with several partners. However, one might consider that not every patient within the European Union has access to all treatment types, including what is often life-saving treatment. At the same time, organs for which no transplant programme exists in a country are typically not even considered for donation.

In order to overcome these disparities, organ donation and transplantation as well as cooperation between Member States are the subject of several measures proposed by the European Commission, such as *Directive 2010/53/EU on standards of quality and safety of human organs intended for transplantation and Action Plan on Organ Donation and Transplantation, and financially supported under the Second Programme of Community Action in the Field of Health (2008–2013)*. The general objective of these measures is to strengthen the cooperation among EU Member States, overcome the organ shortage, and provide access to good quality health care.

## 1.1 ABOUT THE HANDBOOK

This handbook is one of the main results of the European Joint Action called FOEDUS, “Facilitating Exchange of Organs Donated in EU Member States” (Agreement no. 20122101). It is designed to support NCAs in their communication with the media.

The handbook refers to the communication of general information in the field of organ donation and transplantation, including cross-border organ exchanges as well as crisis communication.

While its main purpose is to provide practical guidance, this handbook also contains some relevant theoretical aspects in order to provide a comprehensive overview. It covers different aspects of communication and is designed for the NCA in charge of organ donation and transplantation in EU Member States as well as transnational organisations, as stated in Directive 2010/53/EU. Based on their expertise and knowledge, NCAs and corresponding organisations are considered to be most important disseminators on this topic for the general public.

The communication measures of the NCAs and transnational organisations usually focus on two main areas: the release of general information on one hand, and the provision of information upon request on the other. This handbook intends to support multipliers by referring to all areas of communication, with a special emphasis on their communication with the media (see Figure 2).

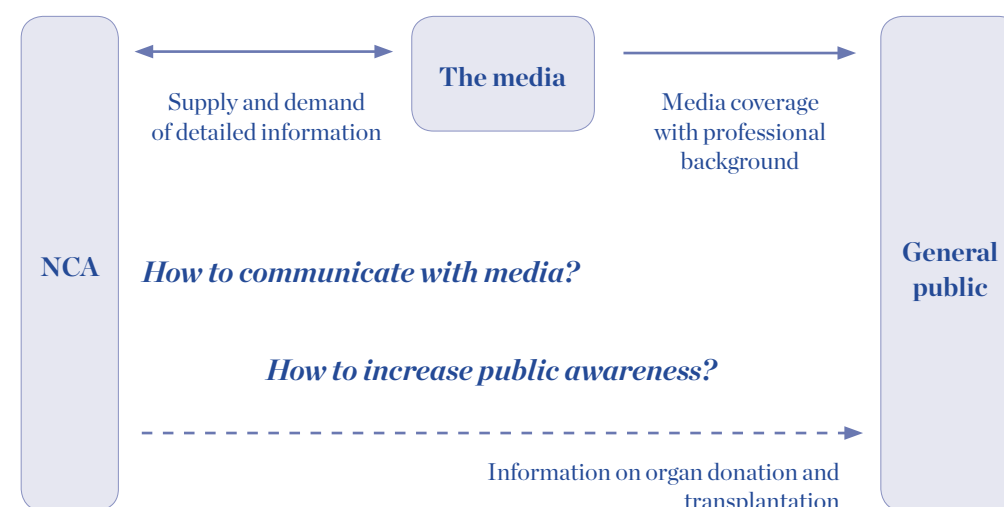


Figure 2: Communication paths for raising public awareness in the field of organ donation

## 1.2 FOEDUS IN THE CONTEXT OF THE EU'S HEALTH POLICY AND STRATEGY

### 1.2.1 EUROPEAN ACTIONS AND MEASURES

FOEDUS is a three-year (2013–2016) Joint Action (JA) funded in 2012. Co-financed by the European Commission and all participating partners, JA are collaborative projects between the European Commission and the European Union Member States initiated for the implementation of strategic measures at the European level. Accordingly, these actions constitute the practical implementation of the EU's strategy.



Europe 2020 aims to turn the EU into a smart, sustainable and inclusive economy promoting growth for all – one prerequisite of which is a population in good health. [http://ec.europa.eu/health/strategy/policy/index\\_en.htm](http://ec.europa.eu/health/strategy/policy/index_en.htm) [last accessed: January 2015]

With the purpose of ensuring comprehensive and consistent implementation, the overall strategy is applied to all economic sectors, such as the health sector (see Figure 3).



Figure 3: Interrelation between the European strategy and health programmes

The European Commission’s current health strategy includes several main objectives such as the promotion of good health in an ageing Europe, protection against health threats, and the provision of dynamic health systems and new technologies. There are three ways in which the European Union’s public health strategy can be implemented. It can be supported by legislative changes, financial instruments, or EU-wide cooperation.

In order to define specific objectives for all sub-areas of the health sector, the Directorate General in charge of Health (DG SANTE) at the European Commission has developed several action plans, such as the *Environment and Health Action Plan*, *Action Plan on HIV/AIDS*, *Action Plan for the EU Health Workforce*, *Better Heart Disease and Stroke Care Action Plan* and, in the field of transplantation, the *Action Plan on Organ Donation and Transplantation (2009–2015): Strengthened Cooperation between EU Member States*. While Directive 2010/53/EU focuses on quality and safety aspects, the Action Plan defines several priorities and divides each priority into various actions: five priority actions for increasing organ availability, three for enhancing the efficiency and accessibility of transplant systems, and two for improving quality and safety. For example, priority actions 4 and 5 (see Figure 4) aim to improve public awareness of organ donation and transplantation and are the main foundations for FOEDUS WP7.

**OBJECTIVE 3 – Increase public awareness of organ donation**

**Priority Action 4:**

Improve the knowledge and communication skills of health professionals and patient support groups on organ transplantation.

**ACTION 4.1**

Incorporate in the Set of National Priority Actions recognition of the important role of the mass media and the need to improve the level of information to the public on these topics.

**ACTION 4.2**

Promote training programmes geared towards health professionals and patient support groups on organ transplantation communication skills.

**ACTION 4.3**

Organise periodic meetings at the national level (competent authorities) with journalists and opinion leaders and manage adverse publicity.

**Priority Action 5:**

Facilitate the identification of organ donors across Europe and cross-border donation in Europe.

**ACTION 5.1**

Collect and disseminate information about citizens’ rights concerning organ donation across the EU.

**ACTION 5.2**

Develop mechanisms to facilitate the identification of cross-border donors.

Figure 4: Extract from the Action Plan on Organ Donation and Transplantation (2009–2015)

## 1.2.2 FOEDUS JOINT ACTION

FOEDUS is a Joint Action funded in 2012 within the framework of the EU's health programme (2008–2013). The action is funded by the European Union and co-financed by its participating partners.

FOEDUS focuses on facilitating collaboration on organ donation and transplantation among national authorities in the European Union as is prescribed in Directive 2010/53/EU and in the Action Plan on Organ Donation and Transplantation 2009–2015 created by the European Commission. The joint action, which aims to initiate improvements at the European level together, is being carried out from May 2013 to April 2016. It involves 18 associated partners and eight collaborating partners (see Appendix I). The associated partners are responsible for implementing the project as they are assigned to different work packages. The collaborating partners represent the advisory board. The main task of the advisory board is to advise the partners during the course of the project, propose improvements where necessary and to evaluate the project's implementation and quality (see Figure 5).

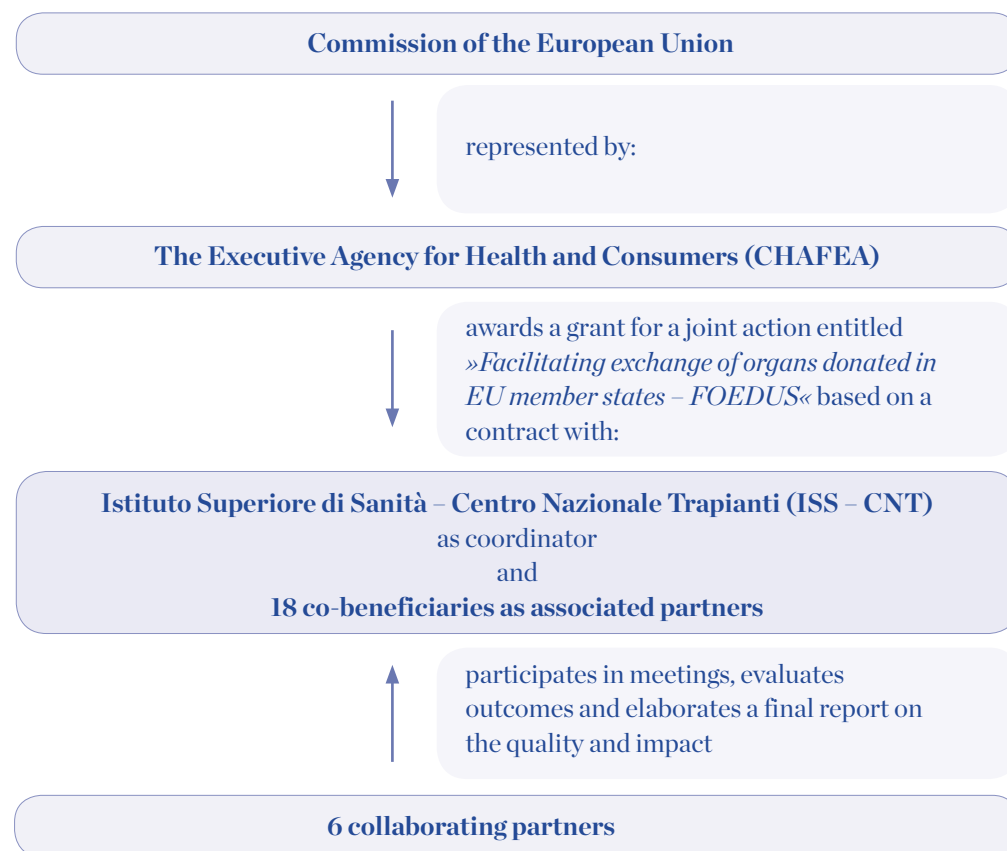


Figure 5: Interrelation between the FOEDUS contractor and partners

Anticipating that cross-border exchange is an important instrument for enabling better access to organs for all citizens in EU Member States, FOEDUS aims to improve the practice of cross-border organ exchange within European Union countries. It focuses on deceased donation and takes the results of the COORENOR EU-funded project (Agreement no. 20091103, implementation period: 2010–2012) into account by referring to one of its key findings, namely, that the present number of exchanges could grow substantially provided that all measures suitable for facilitating the exchange are put in place. Results of the previous EU-funded Joint Action MODE (Agreement no. 20102101) as well as of the EDD project (Agreement no. 20081109) were also taken into account for FOEDUS.

The FOEDUS JA aims to develop a common methodology for cross-border organ exchange, trying to find a way to overcome all of the obstacles and barriers that prevent such cooperation. For this purpose, several core work packages are defined, like the definition of guidelines for cooperation or the consensus on donor medical information. The subdivision into work packages enables a comprehensive approach and encourages optimal use of partial results. Apart from the four core work packages (WP 4 to WP 7), there are three horizontal work packages in charge of overall management of the project (see Figure 6).

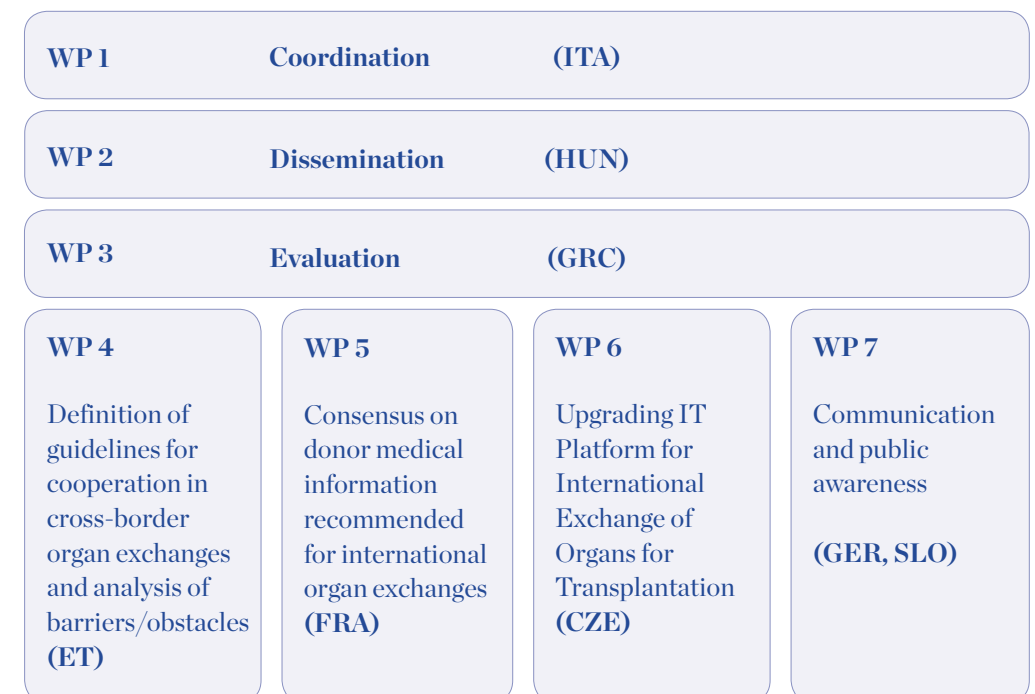


Figure 6: FOEDUS project structure

### 1.2.3 THE DEVELOPMENT OF FOEDUS WORK PACKAGE 7

FOEDUS work package 7 (WP7) co-led by Slovenija Transplant (ST) and Deutsche Stiftung Organtransplantation (DSO) is devoted to communication issues. In the initial phase of the project, the work package is aimed at improving communication on cross-border exchanges within EU Member States. The intention was to develop a communication approach to inform EU citizens about the benefits of international collaboration.

During preliminary discussions, it was decided that the focus of this WP should be broadened since cross-border exchange is closely connected to other topics regarding communication in the field of organ donation and transplantation (see Figure 7).

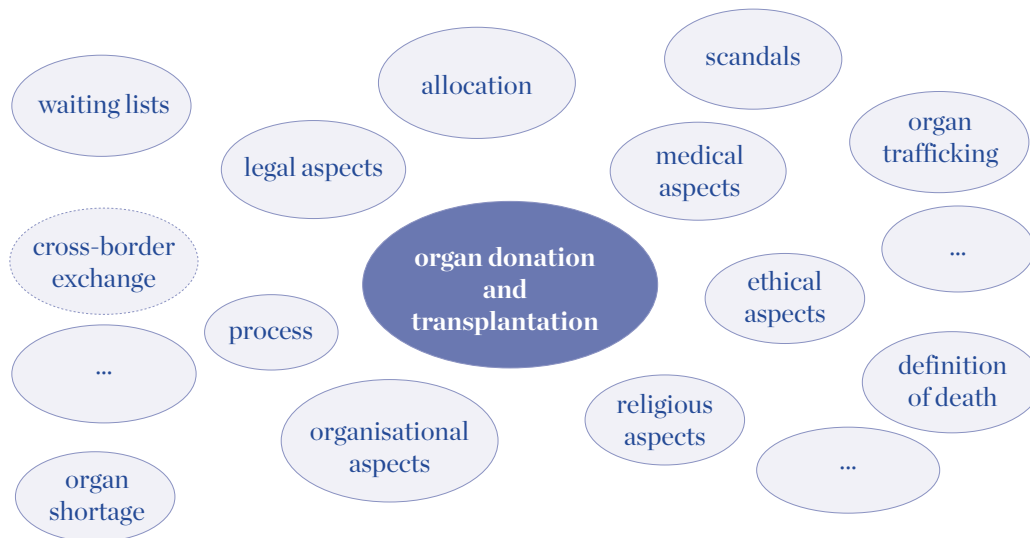


Figure 7: Variety of topics relating to organ donation and transplantation

Further, communication is an important aspect of the European Union's health strategy and, as explained earlier, one priority action for Member States' action individually and together under the EU Action Plan on organ donation and transplantation (2009–2015): Strengthened Cooperation between Member States.

Even though communication is an essential part of the day-to-day operations of NCAs, there is still a need for further research. This was also confirmed in 2012–13 by the ACTOR study, financed by the EU (EAHC/2010/Health/01) to provide an external view on the uptake of the EU Action Plan by Member States, at mid-term (so-called mid-term review).

The ACTOR study, NIVEL 2013, p. 159 Priority actions

#### 4. Knowledge and communication skills of health professionals and patient support groups

Several representatives report a variety of strategies to communicate about organ donation to increase awareness among their populations. This seems somewhat at odds with the formal answers concerning specific activities from the Action Plan that indicate a far smaller extent of activity. Apparently, activities on this topic have been taken up by many countries, but perhaps not all in a very systematic way. A possible strategy to make progress on this Action may be to start developing national communication plans on organ donation. Such plans may benefit from the experience of countries with successful communication activities and from the expertise developed in the context of the European Donation Day. These plans could, for instance, allow for ad-hoc actions and contain strategies on how to react to 'bad publicity'. Making such plans would also entail a strategy to allocate a specific national budget to such actions and therefore contribute to the sustainability of the communication efforts. The work package of the FOEDUS Joint Action focusing on these aspects will help in this regard.

Already in December 2012, the *Council conclusions on organ donation and transplantation*<sup>1</sup> adopted by Health Ministers of EU Member States during the Cypriot Presidency welcomed, so as to increase organ donation rates, “the organisation of national awareness campaigns and European initiatives, such as the European Organ Donation Days and the Journalists Workshops on Organ Donation and Transplantation organised respectively by the Council of Europe and the European Commission”, as well as “the development of best practices and training programmes at national and European level supported by the EU Programme of action in the field of health”. It also recalled “the importance of transparent and comprehensive communication to strengthen public trust in the value of transplant systems based on deceased organ donation as well as on living donations”. EU Health Ministers therefore invited EU Member States:

- to improve awareness amongst patients and their families on the different transplant options, including deceased and living donor transplantation as well as other alternative replacement therapies” and to “improve information on donation and transplantation in general and to engage healthcare professionals in providing appropriate information on organ donation”; and
- “to exchange information on their communication strategies, and to proactively communicate to the general public, including the use of social media”.

<sup>1</sup> Council conclusions on organ donation and transplantation (2012/C 396/03).

Last but not least, in its own document issued for the mid-term review of the EU Action Plan the European Commission recognises that, while different actions have already been taken regarding communication and awareness-raising prior to and during the first years of the EU Action Plan, these initiatives and efforts need to be continued at the EU level (for example, via the Journalist Workshops on organ donation and transplantation organised by the Commission) and further developed and organised at the national level. Co-funded by the Commission, the FOEDUS project is mentioned as the project intended to support Member States on this topic in 2013–2016.

Communication on organ donation and transplantation is a complex matter that entails a lot of difficulties. It requires great attentiveness and is not fully controllable, even for well-established organisations. This impression was constantly confirmed in numerous discussions within the consortium. The results of a preliminary questionnaire provided further proof: the analysis discovered that efforts to increase donation rates by publishing positive events or conducting campaigns have only rarely been evaluated and, if so, they had different results. However, the situation is different with regard to crises and negatively perceived events. Here, a quantifiable influence on the donation rates was detected in several cases. This difference leads to the presumption that donation rates can hardly be influenced by the communication approach that is usually employed. On the other hand, it is known that well-informed people are more likely to agree to organ donation. Therefore, raising public awareness is a key prerequisite for increasing donation rates.

Within the European Union, there is a great variety of responsibilities and legislation for organ donation and transplantation. This is also true for the complex field of communication. While some Member States have communication departments and/or professional support available at any time, the topic is less developed in other member states. In order to provide an approach that benefits all Member States, WP 7 aims to develop a comprehensive approach. With the objective to increase public awareness, the communication approach should focus on general information as well as crisis communication and cross-border organ exchange (see Figure 8).

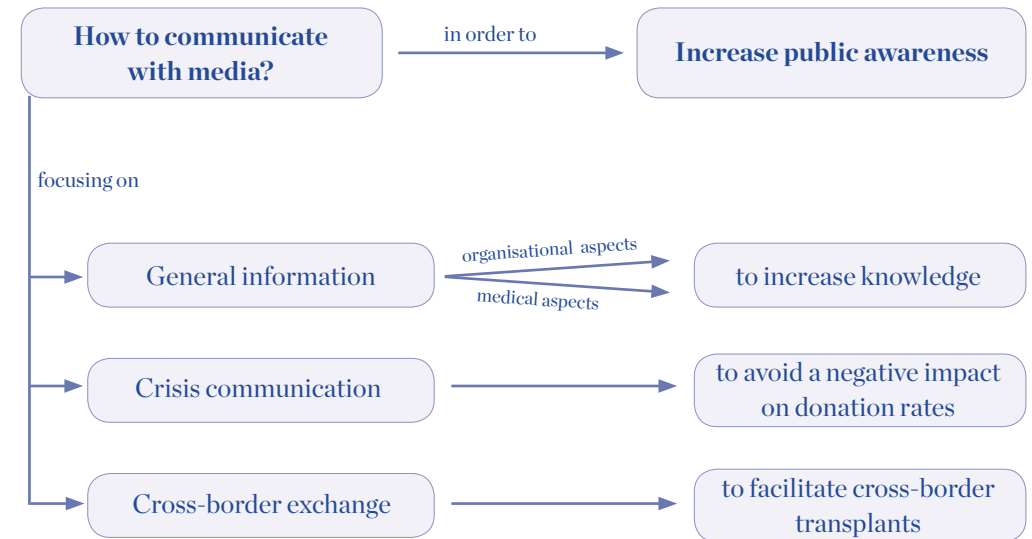


Figure 8: The comprehensive approach of FOEDUS WP7

This strategy is confirmed by the fact that communication is today no longer one-dimensional and static, but multi-dimensional, omnipresent and dynamic. As a result, communication is not limited to one channel, addressee or a certain time, but has to be more flexible and much faster than in the past.



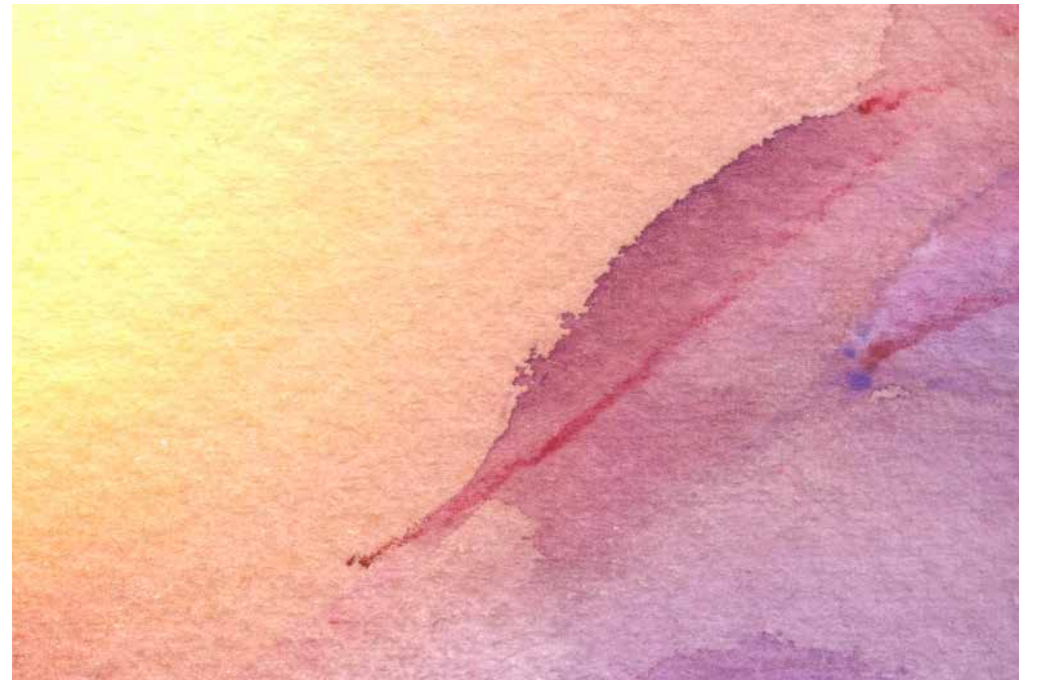
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**PART I:**

**Theoretical approach to communication**



Social marketing constitutes the chosen framework for communication in the context of organ donation and transplantation to raise awareness and inform the general public. In order to ensure adequately designed communication measures, it is considered important to illustrate some general aspects of social marketing.

This part provides a theoretical framework for social marketing in health communications, including:

- a general introduction to the topic of social marketing;
- a demonstration of Maslow's hierarchy of needs as an explanatory model for human motivation;
- a presentation of social cognitive theory as an explanatory model for actions and behaviours;
- a presentation of principles and tools that are applied within marketing and their translation to social marketing; and
- the basic principles of social marketing in the field of organ donation and transplantation.

## 2 SOCIAL MARKETING

Social marketing is understood as the application of marketing principles and techniques in order to influence people's attitudes and behaviours. It is applied, for instance, to environmental protection, health education, social projects, animal welfare etc. Social marketing seeks to contribute to social well-being. In this context, it focuses on the benefits for an individual as well as for society at large. Social marketing tries to convince a target group by appealing to its principles and rationality. Therefore, it implies knowledge from many other disciplines, including sociology and psychology. It attempts to promote a socially desired behaviour, such as non-smoking in public spaces or vaccination. By explaining the advantages of certain actions, it aims to influence the voluntary behaviour of target audiences. While commercial marketing tends to persuade consumers to purchase a certain product, social marketing tries to persuade them to adopt a specific behaviour through the use of argument or evidence. The expected final outcome is the sustainable adoption of new behaviour by changing behavioural patterns.

### 2.1 MASLOW'S THEORY OF MOTIVATION

The focus on changing behaviours by motivation offers a connecting link to Maslow's hierarchy of needs. Based on the assumption that people aim to fulfil their needs and wants, Maslow identified five fundamental levels of needs: physiological needs, safety needs, needs of belongingness, needs for esteem and needs for self-actualisation (see Figure 9). These

five needs can be assigned to deficit and progression principles. Deficit principles refer to elementary needs such as food, sleep and shelter. Those needs will eventually reach saturation. Progression principles, on the other hand, refer to intangible aspects that contribute to the development of one's personality and individuality. Any need that is allied to progression principles cannot ever be fully satisfied.



Figure 9: Maslow's Hierarchy of Needs

The levels of Maslow's hierarchy of needs are:

**Physiological needs:** Primary or natural needs related to self-preservation. Corresponding needs are instinctive such as the need for water, food, sleep and sexual reproduction. Physiological needs are dominant, meaning that they have to be satisfied for any other motivation to become relevant.

**Safety needs:** With the saturation of physiological needs, needs for security and stability arise. Safety needs can be characterised by the absence of major physiological threats. Possible safety-related needs are the need to have a home and to live in a secure environment. Together with physiological needs, safety needs can be assigned to so-called elementary needs.

**Needs for belonging:** As soon as elementary needs are fulfilled, social needs emerge. They describe the need for familiarity and acceptance, e.g. the need to be or become part of a social group. The need to belong can be met, for example, by family, friends and social groups.

**Needs for esteem:** Esteem needs can be divided into internal and external needs. Internal needs refer to values such as success, independence and freedom of choice. In contrast, external needs relate to respect and social recognition.

**Needs for self-actualisation:** Self-actualisation needs are at the peak of Maslow's hierarchy. They constitute the only level that cannot be fully satisfied as it aims to recognise and exploit one's full potential. Needs for self-actualisation reflect one's desire for personal fulfilment and development.

In the context of social marketing, addressing Maslow's needs provides a reasonable approach for understanding people's behaviour. By laying emphasis on all relevant aspects at one particular level, specific target groups can be addressed.

In this respect, it has to be noted that people have different needs and that these needs should be weighted differently according to individual circumstances. Further, needs can change over time. A social marketing measure, for example, that highlights the importance of paediatric vaccinations by demonstrating worst-case assumptions (e.g. infection of measles encephalitis) calls upon parents' urge for survival and self-preservation. By explaining the risk and frequency of fatalities, the positive effects of an immunisation (survival) are highlighted.

Yet the situation is even more complex when it comes to the topic of organ donation and transplantation in the context of deceased donation. Here, Maslow's patterns only apply to a limited extent due to an ambiguous assignment to identified needs.

First and foremost, from the potential donor's point of view there is no perceived direct effect resulting from a positive or negative decision. No reward in terms of meeting one of Maslow's needs seems to be offered. While a vaccination reduces the risk of infection and, therefore, prevents disease, a decision on organ donation does not directly satisfy any everyday needs. On the contrary, all practical consequences of a decision occur only after death so there is – apparently – no benefit for the individual during their lifetime at all.

Another reason for the limited usability of the previously mentioned pattern is that any communication on the topic simultaneously covers more than one hierarchical level. Since organ donation applies after death and is thus always connected with it, needs-oriented communication may suffer from a little inconsistency. For example, if a campaign focuses on the act of humanity (altruism – *self-actualisation*) it will most certainly also indicate that this act can only happen after one's death (*self-preservation* – physiological needs). Or, if a campaign stresses the much greater likelihood of needing a transplant than becoming an organ donor, it simultaneously addresses the levels of *need for safety* (there is an actual risk to health) and *belongingness* (there is a mutual give and take) and, again, *self-preservation* (it is a life or death issue). Due to this ambiguous assignment, changing behaviour by means of persuasion is a highly complex task in the field of organ donation and transplantation.

These factors may provide an explanation for the limited effectiveness of campaigns and other marketing-related measures. They also illustrate possible causes of the difficulties that often arise when communicating about organ donation.

Even though there might be some reasons that question the operability of a Maslow-based approach in the field of organ donation and transplantation, there is still one substantial argument for why efforts should continue. As mentioned before, it can be anticipated that social marketing is crucial for raising awareness. And awareness, in turn, is crucial for creating motivation and subsequently behavioural changes.

## 2.2 SOCIAL COGNITIVE THEORY

Beside Maslow's hierarchy of needs, another model for explaining people's actions and behaviours comes from social cognitive theory. Social cognitive theory tries to explain the principles of human behaviour and, in doing so, also provides an approach for triggering behavioural changes. The theory emerged from the social learning theory developed by Albert Bandura in the 1960s. Within social learning theory, Bandura postulates that learning takes place in a social context. He specifies that people do not only learn upon request or as passive receivers, but also by observing and interacting with others.

Social cognitive theory is built on an analogous assumption. It suggests that the cognitive process of learning happens in a dynamic interaction between an individual and its environment. Further, social cognitive theory claims that behavioural patterns are the result of a cognitive process or, in other words, that behaviours are learned. It may nevertheless happen that learning does not result in a behavioural change. Individuals are able to rely on previous experiences; hence, their willingness to engage in a new behaviour is directly influenced by them.

Bearing in mind that one's behaviour is the result of a cognitive process, it is highly dependent on the affected person and his/her cognitive and affective skills. If a person, for instance, is unable to capture a certain situation, he/she is less likely to adapt any behavioural change that might be connected with that situation. In addition to personal characteristics, the *behavioural aspect* is also an important determinant within a cognitive process. The experiences of an individual as well as his/her attitudes and habits have significant influences on future behaviours. A positive decision to wear a bicycle helmet is, for example, deemed more likely for someone who often rides a bicycle and therefore knows the risks, or someone with a high level of safety awareness.

Finally, also the environment in which a person acts has a considerable impact on his/her cognitive processes. The decision to wear a bicycle helmet depends, among other factors, on access to such equipment. One's *environment* can be subdivided into the physical (climate, water supply, size of room etc.) and social environment (family, friends etc.).

All three factors – person, behaviour, environment – are strongly interrelated and permanently influence each other, and their relationship is thus called triadic reciprocal determinism (see Figure 10). Reciprocal determinism constitutes one core assumption of social cognitive theory.



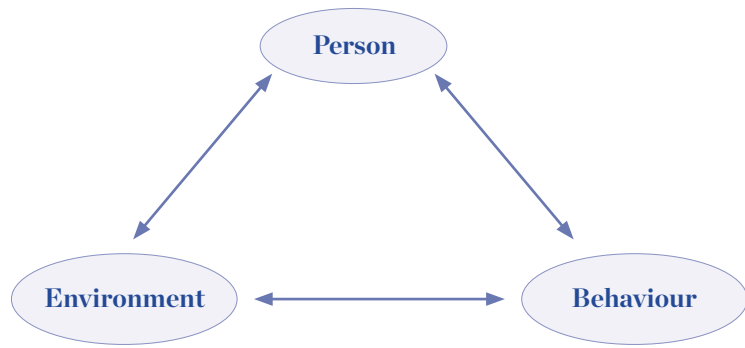


Figure 10: Reciprocal determinism

Another of Bandura's key statements is that people are not driven by a direct cause-and-effect relationship where any behaviour is immediately rewarded or punished. The motivation to learn or maintain a behavioural pattern instead evolves from a set of auxiliary concepts (see Table 1).

Table 1: Social cognitive theory – Concepts

Concept	Description
Behavioural capability	One's ability to perform a desired behaviour
Outcome expectations	Positive assessment of the consequences of a behaviour
Self-efficacy	The belief in one's capability to perform a specific behaviour
Modelling	Behavioural acquisition through observation of actions and outcomes of others
Reinforcement	Likelihood of maintaining or rejecting a behaviour according to the feedback given

Reciprocal determinism as well as the above-mentioned concepts provide a useful starting point for the development of social marketing measures. Within a strategy on paediatric vaccination, for example, several concepts of social cognitive theory can be operationalised: communicating the positive effects of a paediatric vaccination will support one's outcome expectations. And a campaign that promotes the coverage of costs for such vaccination can serve as positive reinforcement.

Due to its comprehensive approach in terms of initiating and maintaining behaviours, social cognitive theory is frequently applied in the field of health communication. Many models have been developed under the concept of the social cognitive theory.

## 2.3 MARKETING PLANNING PROCESS

After having presented Maslow's hierarchy and Bandura's social cognitive theory as explanatory models for human motivation and behaviour, the concept of marketing will be presented by means of the marketing planning process. The process summarises marketing related efforts in chronological order. It can be applied to all branches of marketing. The planning process includes a description of the current state, a characterisation of the goals, strategies and measures, and a specification of the evaluation concept (see Figure 11).

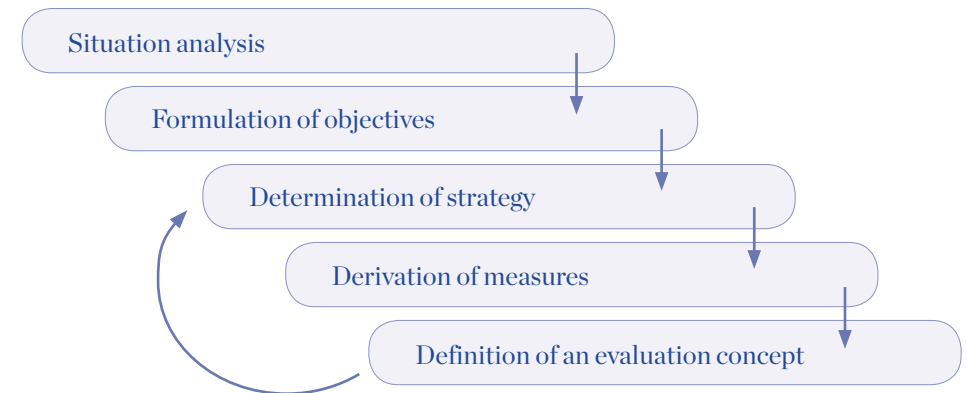


Figure 11: The Marketing Planning Process

**Situation analysis:** The situation analysis provides an appropriate start for any marketing related activity. In combination with a precise definition of the task, situation analysis helps achieve a profound understanding of the capabilities within a particular area.

**Formulation of objectives:** In order to change the current status identified in the situation analysis, change requests have to be articulated. If those requests include information on specific contents, extents and timings, they can be considered objectives. Accordingly, a possible marketing objective would be to gain a 25% (*extent*) market share for a certain product (*content*) within 5 years (*timing*). For social marketing, a possible objective would be to increase the share of paediatric vaccination in a given region by 50% by the end of a year.

**Strategy formulation:** After determining the objectives of a marketing programme, actions for their achievement have to be derived. The basic orientation of all actions can be described as a strategy. In relation to the above-mentioned examples, a company could follow the strategy of being a price leader, i.e. increasing its market share by offering a product at the lowest price; or, with regard to paediatric vaccination, by eliminating doubts about the safety of the vaccine.

**Characterisations of measures:** A marketing strategy can be implemented by way of various actions and activities. A well-established set of actions is the marketing mix. It is applied to transform strategic decisions into actions. The marketing mix, respectively the 4 P's model, will be presented in more detail below (see Chapter 3.4).

**Evaluation concept:** The implementation of a marketing strategy is typically supplemented by a market control system in order to monitor and evaluate the efficiency and effectiveness of all measures.

Implementing a plan step-by-step as presented here is not a necessary requirement for successful marketing. However, it serves as a starting point for effective marketing management.

## 2.4 SOCIAL MARKETING MIX

With regard to the marketing planning process, the actual implementation of marketing actions can be assigned to the “marketing mix”. As with the marketing planning process, the basic approach does not distinguish between commercial and social marketing. With the exception that social marketers do not try to sell economic success, they use similar practices and tools as commercial marketers do. One of them is the marketing mix, which constitutes the practical realisation of various actions with regard to product, price, promotion and placement. The so-called 4P's are intended to interact, meaning they should be aligned and coordinated. They define the key elements in order to control a process of exchange. The 4P's of the marketing mix are:

**Product:** A tangible or intangible item on offer. In order to be successfully offered for exchange, a product has to be clearly defined.

**Price:** The pricing policy defines the conditions in which one can obtain an offered product.

**Promotion:** All measures that are intended to communicate the benefits of a product to internal and external reference groups.

**Place:** Decisions on how a potential consumer can obtain a product and activities to make it available.

Although at first glance the 4P's of the marketing mix seem to be basically attributable to commercial marketing, they can also be applied to social marketing. When developing a social marketing programme, similar approaches are considered (see Figure 12). Accordingly, the 4P's of the marketing mix can be applied as follows:

**Product:** Ideas, attitudes or behaviours beneficial for an individual as well as for society. The product can sometimes be supported by tangible items such as vaccines, donor cards or condoms.

**Price:** Costs of adopting a new idea, attitude, behaviour or practice. Costs can be monetary as well as emotional, psychological or time-related. Even though quitting smoking, for example, has a positive financial impact, the cost of quitting can be considered to be relatively high. Costs can be determined by the emotional cost of giving up something that has previously been enjoyed. In order to support an adequate cost-benefit ratio, social marketing programmes need to focus on the benefits while making it as easy as possible to adopt the intended behaviour.

**Promotion:** Like with commercial marketing, it refers to all measures that are intended to communicate the benefits of an idea, attitude, behaviour or practice.

**Place:** A description of how an idea or attitude reaches the target group. It requires a clear differentiation of the intended behaviour as well as the target group. In addition to well chosen access points, a social marketing programme should also provide information on where to obtain further information or assistance.



Figure 12: The Marketing Mix applied to Social Marketing

There are models that expand the original marketing mix with some additional P's, such as policy, partnership, performance etc. Yet, for the sake of clarity, this handbook will limit itself to the original 4P's model.



## 2.5 SUMMARY AND CONCLUSION

Social marketing provides an appropriate foundation for communication measures in the field of organ donation and transplantation. Its suitability is confirmed by the fact that social marketing seeks to contribute to social well-being. In this context, it focuses on appealing to target groups' principles and rationality. While commercial marketing tends to persuade consumers to purchase a certain product, social marketing tries to encourage through the use of argument and evidence. Similar principles apply to the field of organ donation and transplantation. Here, communication measures often aim to persuade people to make a decision on organ donation.

Nevertheless, there are also some pitfalls when using social marketing as a foundation. Maslow's hierarchy of needs, for instance, provides an appropriate philosophy for social marketing, but only to a limited extent is it applicable to organ donation and transplantation. There are several explanations for this, including that communication in organ donation and transplantation apparently does not offer a direct reward in terms of meeting one of Maslow's needs. Social cognitive theory provides another basic model for activities related to social marketing. The model is for triggering and maintaining behavioural patterns. Nevertheless, social cognitive theory refers to a relatively complex theory where the relationship between person, behaviour and environment has to be constantly respected.

The absence of a clear assignment to either of the presented concepts underlines the complexity of communication in the field of organ donation and transplantation. It thus provides a good reason for more accurate investigations in this area.

Social marketing provides an appropriate foundation for communication measures in the field of organ donation and transplantation. Nevertheless, there are also pitfalls, which underline the complexity of effective communication and the need for a clear understanding.

## 3 SOCIAL MARKETING IN THE FIELD OF ORGAN DONATION

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### 3.1 ACTIVE BEHAVIOUR CHANGE

Social marketing has proven to be a useful approach to social change. It is not a theory but a framework that draws knowledge from many disciplines to understand how to influence people's behaviour. Applying the social marketing framework to the organ donation field requires abandoning the expert's mind-set that organ donation is intrinsically good so that, if it fails to gain support, the problem lies with ignorant and unmotivated people who need more information and louder campaigning. More information about organ donation does not necessarily lead to behavioural change; in fact, it might lead to a willingness to donate, but a willingness to donate may not be a strong predictor of registering as a donor or becoming a real donor. Thus, raising awareness is not enough to stimulate action.

The organ donation field is confronted with an imbalance between organs available for procurement and the number of people waiting for transplantation. Demand for viable organs has grown exponentially in the last few decades and donation rates have not kept pace with the demand. This is a problem the social marketing approach would address by initiating active behaviour change. The social marketing approach would aim to find ways to narrow the gap between organ demand and supply on the precondition that organ transplantation remains totally voluntary, dependent on people's willingness to donate.

In general, social marketing would need to influence organ donation behaviour on three levels (see Figure 13).

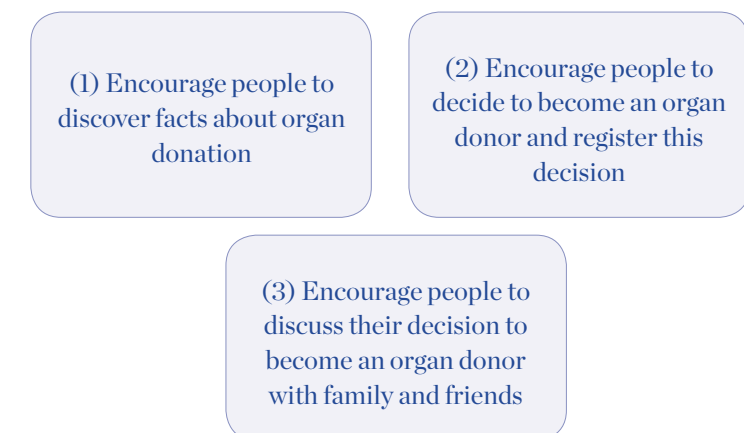


Figure 13: Organ donation behaviours to be encouraged

These behaviours are interrelated, yet a social marketing approach would tackle them separately because they might be linked to a number of specific barriers that need to be studied and addressed.

### 3.2 PEOPLE-CENTRED APPROACH

Organ donation is a peculiar health promotion issue primarily because it is embedded within the oppositional relationship between life and death. Programmes for promoting postmortem organ donation deal with behavioural change that requires people to anticipate their own death, which involves their cognitive and affective processes. Inviting people to engage in recommended behaviour like discussing organ donation with family members, registering as an organ donor or giving a next-of-kin consent to organ donation is thus an extremely complex issue that distinguishes the promotion of organ donation from all other health-related promotions.

The social marketing approach is people-centred or 'end-user-driven' and inclined to understand the characteristics of organ donation for a particular group of people. It is based on the premise that there is no such thing as a general population and a universal appeal. Factors that influence pro-organ donation or anti-organ donation behaviour vary greatly between groups of people even in the context of a strong national identity, relatively homogeneous cultural background and general public support for organ donation. Differences with respect to patterns of knowledge, motives, concerns underlying willingness to donate organs and perceived availability of pro-organ donation behaviour result in the fact that centrally designed organ donation campaigns are unlikely to be effective.

Thus, the first step in a social marketing approach is to understand organ donation from the perspective of people, their everyday lives, values, knowledge, beliefs, aspirations, fears, but also structural circumstances.

The principal questions to be asked in a social marketing approach to organ donation are (see Figure 14):

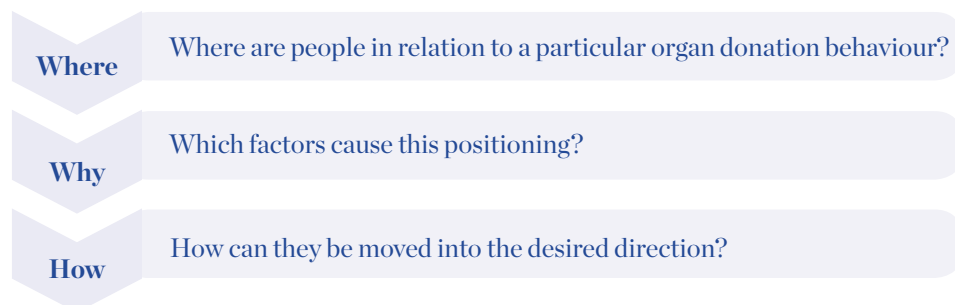


Figure 14: Initial questions in a social marketing approach to organ donation

Answers to these questions can be found with the help of theories of change.

### 3.3 THEORIES OF CHANGE

It is crucial to understand the social dynamics that influence individuals to participate in organ donation behaviour, namely to discuss organ donation with family members, register as an organ donor, or give consent for the organ donation of a deceased family member. Numerous studies have analysed particular aspects of these behaviours and included them in models of behaviour. Behaviour models, such as the organ donation willingness model (e.g. Morgan SE, Miller J, 2002), aim to explain why people behave the way they do and help us understand behaviours related to organ donation by identifying factors that influence these behaviours, like attitudes, beliefs, knowledge, self-efficacy, social norms and socio-demographic factors. Such models are important for social marketing insights into the organ donation phenomenon, yet theories of change are also needed to develop understanding of how organ donation behaviours can change and what might influence them.

Theories of change are abundant and differ in their complexity and the level on which they contemplate behaviour change: individual, interpersonal, community and system level. In the table below, we present some theories of change in relation to the principal questions asked in the process of planning social marketing interventions for solving social problems (see Table 2).

Table 2: Theories of change in relation to the principal questions asked in the process of planning social marketing interventions (adopted from Hastings and Domegan, 2013)

Principal social marketing question	Social change theory	Key principles
Where	Stages of change theory or transtheoretical model	Behaviour change is a gradual multi-stage process.
Why	Social cognitive theory	Social context matters.
	Social norms theory	What other people do around us matters.
	Social epistemology theory	Knowledge has a social as well as a personal dimension.
	Social ecological theory	Everything is connected so the smallest act can have massive repercussions.
	Social capital theory	A sense of belonging to and trust in our communities is vital.
How	Exchange theory	We look for benefits when considering change.

All planning of interventions to promote organ donation demands formative research of organ donation behaviour in a particular society in order to understand its appearance and dimensions and to identify different subgroups; for instance, those inclined to influence (e.g. medical staff, health journalists, online health community moderators, leaders of religious groups) and those likely to be influenced (e.g. patients, families).

Segmentation of the ‘general’ population is a necessary step in social marketing planning to ensure that interventions are tailored to language and the circumstances of a certain group of potential donors; their needs, wants, knowledge, resources, values, habits etc. Several criteria can be used to segment the population into potential target subgroups for promoting organ donation: (1) personal characteristics (demographic, psychographic variables); (2) past behaviour (proximity to the desired behaviour that can be detected with stages of change theory); and (3) the benefits sought (psycho-social benefits that can be linked to a decision to register as a donor).

### 3.4 STAGES OF CHANGE THEORY

This theory, also known as the Transtheoretical model of behaviour change, was developed by Prochaska and DiClemente (1992). It is frequently used in public health interventions aiming to demonstrate that a change in behaviour is a process and not the result of a simple decision. The model suggests that we move through five distinct stages, from ignorance of or indifference towards the proposed behaviour through planning to accepting the proposed behaviour: pre-contemplation, contemplation, preparation, action and maintenance, with a possibility to relapse in any of the stages (see Figure 15).

People move through these stages in different ways, they might enter the process at any stage, they might exit it and re-enter the process at some other stage. This model helps identify people’s proximity to particular organ donation behaviour, like registering as an organ donor or discussing organ donation with family members, and reminds that these vary between individuals and over time. Each stage requires specific interventions to encourage people to move towards the next stage and, finally, to the behavioural goal (see Table 3). Thus, the model is useful for practitioners to reduce the complexity of a change in organ donation behaviour and to understand where a particular population segment is in relation to proposed organ donation behaviour. Many campaigns for promoting organ donation behaviour blindly assume that people are always in the first stage (ignorance of or indifference towards organ donation behaviour) and that all they need to register as an organ donor or to talk about this with their family is enough information and a communicative push. But this is not the case. More information about the behaviour per se does not necessarily lead to this behaviour being engaged in.

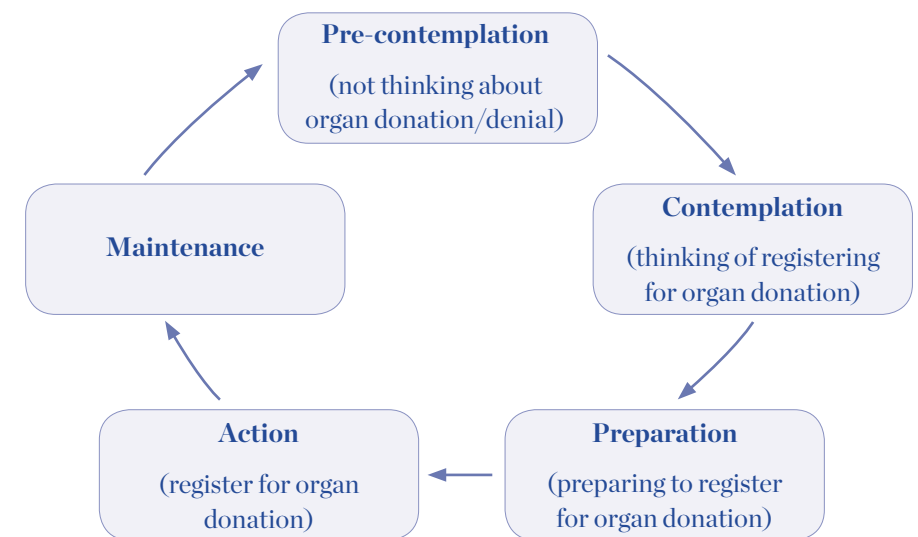


Figure 15: Stages of change in registering as an organ donor

Table 3: Stages of change

Stage of change	
Pre-contemplation	<p>People may be aware of organ donation behaviour (e.g. registration as an organ donor; discussion about the decision to become an organ donor with family members) but are not interested in it.</p> <p>In this stage, we need to know what people know about organ donation, how detailed and correct their knowledge about organ donation is. To move a person from this stage to the following one, they need to be aware of organ donation, its benefits for society and the related procedures.</p>
Contemplation	<p>People are aware of organ donation and are consciously evaluating the personal relevance of organ donation behaviour.</p> <p>To move a person from this stage to the following one, we need to be aware of the barriers to and incentives for particular behaviour related to organ donation. We need to explore which questions a person has when they are thinking to change their behaviour concerning organ donation. Which benefits and costs do they perceive when thinking to invest their time in changing their behaviour. In this stage, interventions need to focus on the benefits of a change in behaviour. Different people need to be reminded of various benefits according to their value system and life situation.</p>
Preparation	<p>People have decided to act and are trying to gather the means they need to carry out the desired behaviour (e.g. information about where to register as an organ donor; support in starting a family discussion about organ donation).</p> <p>In this stage, a person might search for information about organ donation on Internet forums, or inform their friends about their intention to register as an organ donor. In this stage, practitioners need to find ways to support a person in their willingness and intention to register as an organ donor or in discussing organ donation with their family. The recommended behaviour needs to be perceived easier than the alternative behaviours; since many perceived barriers to the recommended behaviour need to be removed.</p> <p>Communication interventions and other promotional activities can minimise the barriers, but some structural issues need to be addressed as well (e.g. an easy procedure for registering and un-registering for organ donation).</p>

Action	<p>People try to behave in accordance with the proposed behaviour, e.g. they register as a donor; they start talking about organ donation with members of their family.</p> <p>A person evaluates the pro and cons of the newly proposed attitude. All health professionals working in the field of organ donation and transplantation can encourage and reinforce a person to act differently and to adhere to the new behaviour.</p>
Maintenance	<p>People are committed to the new behaviour and have no intention to regress (e.g. people continue the family discussion about their decision to become a potential organ donor as long as they achieve understanding about and acceptance of their decision).</p> <p>In this stage, it is important to ensure that this behaviour is positively evaluated by the important others and larger society. The mass media plays an important role in mediating good examples and in building a collective memory which is in support of organ donation.</p>
Relapse	<p>In all of the stages, people can change their minds and decide to return to some other stage, even to the first one (e.g. after their initial discussion about organ donation with their family members they decide they are not ready and not interested in discussing organ donation with family members at this point in their lives).</p>

This model can be helpful in initial segmentation of the population since intervention strategies should be tailored according to the position in the behaviour change process. However, this model does not offer guidance in understanding why people are in a particular stage relative to the proposed behaviour, and which factors need to be addressed to encourage them to move on to the next stage. Several theories can help us understand these positions, one of which (social cognitive theory) was introduced in the previous chapter. It is worth mentioning here that EU Member States differ in the ways their systems of consent for organ donation are structured (opt-in, opt-out or a mixed system). Some countries have a system of donor cards, others not. Contemplating organ donation behaviour change through the above model should thus take these specifics into consideration.

### 3.5 EXCHANGE THEORY

When we find answers to the questions about where in relation to the proposed behaviour and/or attitude particular groups of people are and why they are there, we try to identify answers to the question of how to move target groups towards the behavioural goal. This part of the formative research is guided in social marketing by the principles of exchange theory. Exchange theory assumes that in normal circumstances every behavioural option has



alternatives that people assess, and they select the one which provides them with the most benefits. Preferred behaviours thus have competition. Social marketers need to acknowledge the competing factors that get in the way of the preferred behaviours.

In social marketing, the exchange is primarily symbolic, involving the transfer of psychological and social entities that are relatively intangible, yet crucial elements of every exchange. To register as an organ donor is to decide to enter into a mutually beneficial exchange relationship with, for example, transplant organisations or patients that are in need of suitable organs. They enter this exchange process voluntarily because they believe it is appropriate or desirable to develop a relationship with the other party.

Exchange theory conveys at least two important messages for organ donation organisations: (1) it implies that organ donation organisations need to recognise potential donors as people with whom they need to build relationships; (2) organ donation organisations need to know what they can offer to the particular groups of people they invite to participate in the exchange process; they need to discover what these groups of people value and what they can be offered in exchange for their attention, contemplation about organ donation and registration as an organ donor. This assumption points to another crucial concept in social marketing: value creation. Activities that make people feel better or more respected tend to be valued and can affect their behaviour.

### 3.6 A SOCIAL MARKETING APPROACH TO PROMOTING ORGAN DONATION

Applying the social marketing approach to the promotion of organ donation and transplantation means that we need to:

- think beyond communications;
- set behavioural goals (e.g. encourage people to discover facts about organ donation; encourage people to register as an organ donor; stimulate people to discuss organ donation and their decision to become an organ donor within the family and with close ones; encourage journalists to report about organ donation according to specific guidelines);
- define and choose target groups (e.g. health journalists and editors of important news media; leaders of religious groups; parents);
- make thoughtful use of theory;
- think about individual and structural factors that influence the preferred behaviour; pay careful attention to the competing factors (identify barriers to and incentives for the behavioural goal);
- design attractive motivational exchanges with chosen target groups;
- acknowledge the mass media and entertainment industry as a possible ally and/or competitor in promoting organ donation; and
- think and act systematically.

Social marketing is often mistakenly confused with one or several techniques that social marketing programmes might use, like social advertising. The figure below demonstrates the relationship between the social marketing principles, concepts and techniques (see Figure 16). The foundation of social marketing lies in facilitating the social good and delivering individual and social value creation through exchanges, social offerings and structural change. The second level presents social marketing concepts like social/behavioural influence, people (end-user, participants, civil society, citizens) orientation, social offerings (idea, product and service) and relationship- and network-building. The most visible level of social marketing is just the peak of the social marketing mountain and entails social marketing techniques and tools like systematic planning, competition analysis, insight-driven segmentation, branding, integration intervention mix, communication, evaluation etc.

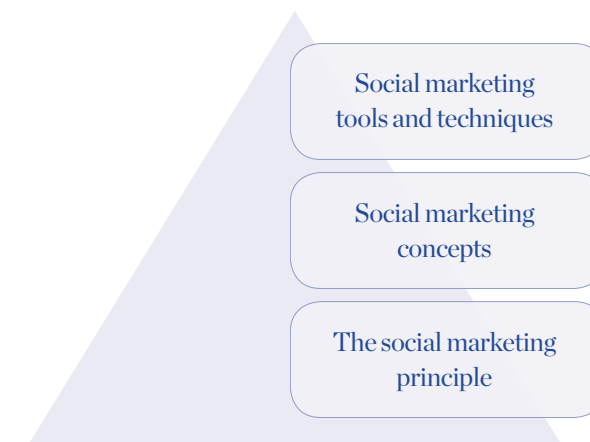


Figure 16: Social marketing principles, concepts and techniques hierarchy model (adopted from French and Gordon, 2015)

## FURTHER INFORMATION

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**PART II:**

**Communication – An analysis of studies**



The following chapters provide:

- a conception of an analysis of studies;
- a description of the literature research;
- a categorisation of the results;
- a presentation of the general results; and
- a presentation of the findings according to a previously developed categorisation.

## 4 RESEARCH METHODOLOGY

The literature search was carried out in order to identify papers dealing with positive or negative experiences in communication. The search terms were “organ donation”, “transplantation”, “communication”, “campaign”, “media” and “evaluation”. Several search engines were used, including PubMed, SciVerse SCOPUS, google.scholar and MedPilot. The search was performed in August 2013. Due to the limited extent of studies, which in turn results from the comparatively young age of transplantation and the even more recent knowledge of the existing organ shortage, no time limit was set when searching for literature. Publication dates emphasise this fact by reflecting the subject’s newness. One study to be mentioned in this context is Horton and Horton’s publication from 1990. Their work is often referred to as one of the first studies dealing with the communication of organ donation and organ donation willingness.<sup>2</sup>

In the initial review, special attention was paid to publications that were particularly often quoted within the findings. As those publications can be considered a basic reference, they were also taken into account for the following literature research. Examples of such fundamental works include Horton and Horton (1990), Kopfman et al. (1998), Morgan et al. (2002) and Feeley and Moon (2009).<sup>3,4,5</sup>

## 5 RESULTS

The literature search yielded 37 publications (see Appendix II).

A detailed review of the results showed that the publications differed significantly in terms of their design and objectives. While some publications focus directly on organ donation and organ donation willingness, others merely try to explain certain effects by using the example

of organ donation. Also, some publications describe campaigns that were actually carried out, while others refer to trials conducted for this exact purpose. A further subdivision was made on the basis of relevance as some publications focused on special aspects like, for instance, registration in offices of the American Department of Motor Vehicles (see Figure 17).

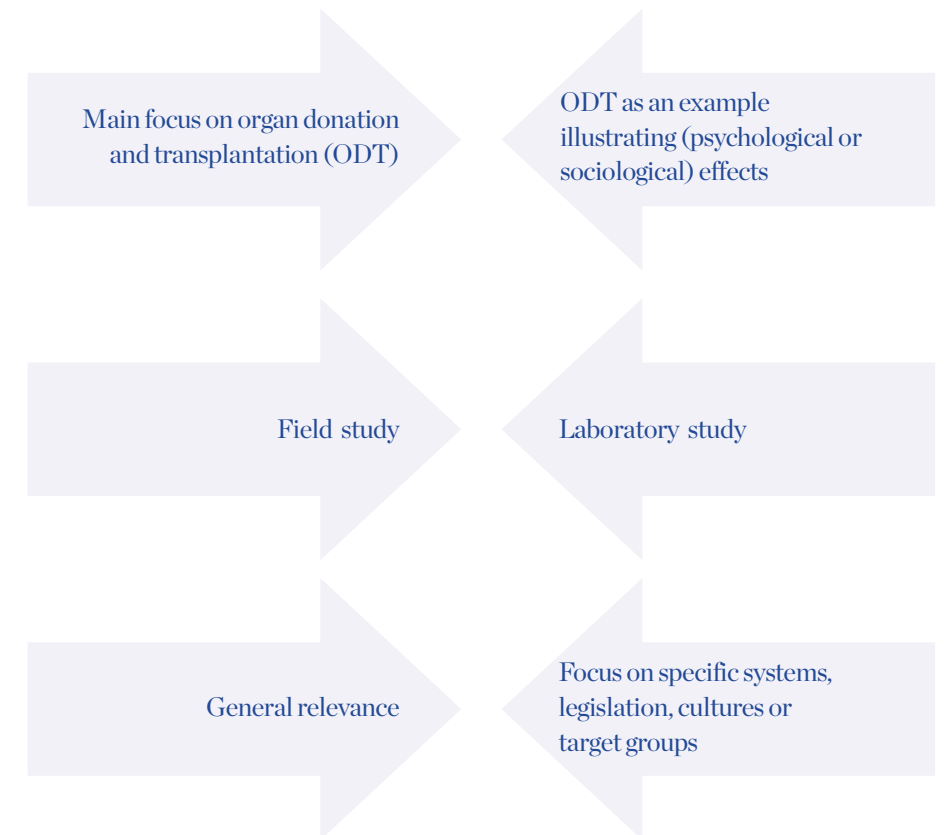


Figure 17: Results of the initial screening of literature

As a result, a rough classification regarding the main objective was made. The set classification categories were “theory-based publications”, “practice-oriented publications” and “publications of limited relevance”.

### 5.1 THEORY-BASED PUBLICATIONS

Articles assigned to the category “theory-based publications” aim to pinpoint certain correlations such as psychological or sociological effects. For example, they try to explain what composes or influences people’s intentions or behaviours. Among such publications, the reference to organ donation often appears to be auxiliary. Sometimes, it even only serves as a «means to an end», implying that the main purpose is to describe certain effects, not the

<sup>2</sup> “One of the first investigations of this type was conducted by Horton and Horton [...]”; Weber et al. (2006), p. 68.a

<sup>3</sup> Horton and Horton were the first to propose such a model [...]”; Morgan et al. (2002), p. 255.

<sup>4</sup> Horton, Horton (1990).

<sup>5</sup> Kopfman et al. (1998).

<sup>6</sup> Morgan et al. (2002).



actual promotion of a behavioural change. Theory-based publications provide important information for planning a campaign by showing conditions that can either stimulate or hinder the willingness to donate.

## 5.2 PRACTICE-ORIENTED PUBLICATIONS

Publications are categorised as practice-oriented when they refer to the evaluation of a campaign that was actually conducted. They are also considered to be practice-oriented if they provide some practical and operational recommendations for carrying out campaigns. The purpose of practice-oriented publications is to describe activities and their impacts rather than analyse their psychological or sociological effects.

## 5.3 PUBLICATIONS OF LIMITED RELEVANCE

According to the above-mentioned specifications, some publications were considered to be irrelevant. They were excluded from further analysis and assigned to the category “publications of limited relevance”. The reasons for this allocation are diverse, including a lack of reference to communication measures or a too narrow focus on specific systems, legislation, cultures or target groups. Please note: assignment to this category does not correspond to a qualitative assessment of the publication.

## 6 DISCUSSION

Presented below are the findings of an analysis of studies that was conducted as one milestone of FOEDUS WP 7. The presentation is divided into general findings and detailed results. While the former refer to the overall findings and their characteristics, the latter seeks to provide answers to the research questions.

The literature search yielded 37 publications. They were, as mentioned before, classified in three categories. Nine publications were assigned to the category “theory-based publications” and 11 to “practice-oriented publications”, while 17 publications were excluded from further analysis as they were considered to be of limited relevance. The remaining publications were then analysed in order to obtain an overview of the current state of the art as well as some practical recommendations for campaigning. The analysis quickly revealed the need to adjust the milestone’s objectives. There are various reasons for this. One of the main ones is the limited number of evaluated campaigns. Although communication campaigns on organ donation and transplantation are quite common, only a few have so far been evaluated. The small number of results means limited validity. Another restrictive factor is the large proportion of studies performed in experimental conditions. These studies were

conducted in order to verify or reject certain hypotheses. They typically entailed small trials which were purpose-built for evaluating or analysing certain relationships. Public campaigns, in contrast, were rarely considered.<sup>8</sup> Considering the nature of the studies examined, the goal of providing an overview of the current state of the art in evaluating the effectiveness of campaigns could only be achieved to a limited degree. Another limitation is that most of the publications refer to student samples. For instance, in seven out of ten empirical studies trials were performed in a university or a school (see Table 4).

Table 4: Sample sizes and characteristics of studies considered for the present analysis

	Reference	Sample Size	Characteristics
1	Conesa et al. (2003)	2000	Adults
2	Gäbel, Rehnqvist (1997)	1000	Citizens
3	Hart LaVail et al. (2010)	426	Students
4	Horton, Horton (1990)	481 465	Students (undergraduate + MBA) Adults
5	Kopfman et al. (1998)	90	Students (undergraduate)
6	Morgan et al. (2002)	798	Employees
7	Reinhart et al. (2007)	189 318 433	Students (undergraduate)
8	Schulz et al. (2000)		Pupils
9	Weber et al. (2006)	370	Students (undergraduate)
10	Yoo, Tian (2011)	429	Students (undergraduate)

Questionnaires and surveys were specially designed and, in many cases, accompanied by an educational cover letter or another form of introduction. The trials were less about the promotion of organ donation than investigating the reactions. This approach may have an influence on the results and create an inaccurate image. As young people are considered to be more in favour of organ donation, the general validity might be reduced compared to a ‘real-life’ campaign.<sup>9</sup> The selection of the trial participants further demonstrates the focus

<sup>8</sup> Only 3 publications refer to an actual public campaign.

<sup>9</sup> This assumption is supported by several publications that were excluded from the analysis due to their special focus. The excluded publications state that the “[...] survey results emphasized that students were more in favor of organ donation than is the general population...”; Manyalich et al. (2010), p. 119. This might be because “[...] children and young adults are thought to be free of prejudice and are easily taught new concepts...”; Cantarovich et al. (2012), p. 13.

of the current research. Since they mainly take part in educational institutions, this might indicate the basic level of the research.

Due to the mentioned restrictions, the following comments are not claimed to be complete. Nevertheless, the results may be considered as significant.

## 6.1 GENERAL EFFECTIVENESS

The following section sets out the results of the literature analysis. First, an overall assessment regarding effectiveness will be given. To prevent any subjective judgement, the general impression is supported by a meta-analytic study. The results of both relevant categories will then be presented by summarising the basic contents and results. The section ends with recommendations for how to perform an effective campaign. In order to assess overall effectiveness, special reference should be made to the publication by Feeley and Moon (2009). They analysed 23 campaigns and 16 studies in a meta-analysis. In the course of comparing, special attention was paid to the degree of campaign exposure, the focus on ethnic minorities, the modalities (mass media/mixed/interpersonal communication) and publication bias (published/unpublished). The analysis showed a 5% overall increase in campaigning effects over control groups. Regarding campaign exposure, Feeley and Moon found no evidence that an increase would lead to a bigger effect size. Similar poor outcomes were stated for minority-focused campaigns as well as different modalities and publication bias. Although Feeley and Moon's findings only indicate small effect sizes, they also point to the general effectiveness of campaigning.

Referring to the previously mentioned classification, the publications' main results will now be pointed out below.

## 6.2 THEORY-BASED PUBLICATIONS

The already mentioned study by Horton and Horton published in 1990 is considered to be fundamental research on organ donation willingness. In their study, they conducted a survey to identify the level of public knowledge concerning organ donation. Assuming that "the decision process involved in such decisions [i.e. becoming a donor] is constructed upon a strong cognitive base",<sup>10</sup> they tested whether knowledge was a determining variable for being or becoming a donor. Altogether, 21 true/false questions were presented to students (N1 = 481) and a mail survey on knowledge was administered to adults in the community (N2 = 465). Horton and Horton's findings indicate that knowledge is an important

variable for becoming a donor. They also discovered four major knowledge gaps negatively affecting the willingness. These gaps concern religious aspects, medical issues (i.e. the concept of brain death), the assignment of responsibilities and organisational aspects. They conclude by recommending an examination of whether an increase in knowledge will lead to an increase in the supply of organs donated. Another study with a similar purpose was conducted by Morgan et al. (2002). They developed and tested a model of organ donation willingness. The model expands previous models, such as that of Horton and Horton, by including more variables and additional interrelations (see Figure 18). In their model, organ donation willingness is directly influenced by attitudes, knowledge and perceived social norms. At the same time, knowledge and perceived social norms have a multiple impact as they also influence the attitude of an individual. Further, the preceding influencing variable is information exposure as well as an individual's personal value system.

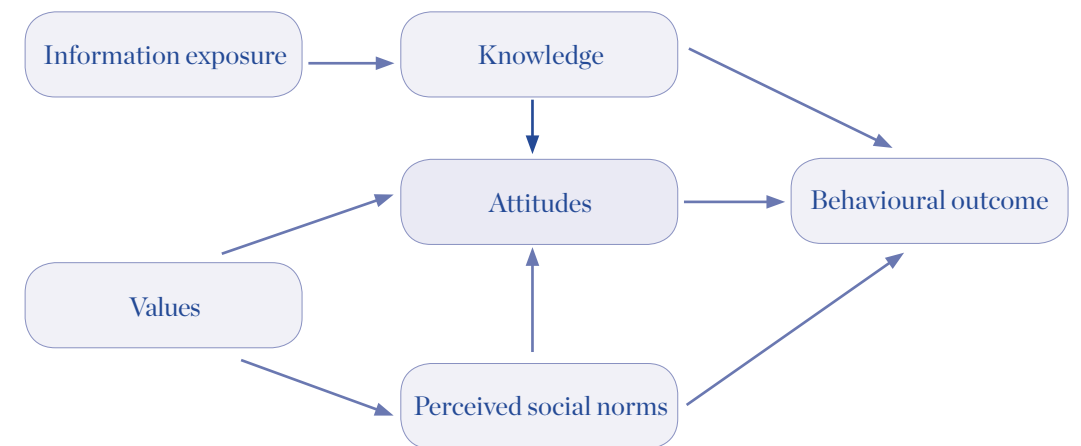


Figure 18: Organ Donation Model (adopted from Morgan et al., 2002)

The model was tested in an actual campaign through a pre-test/post-test comparison. Therefore, employees (N = 798) were asked before and after an 8-month campaign using both multiple message strategies and multiple communication channels (billboards, websites, educational sessions etc.). The calculation was conducted twice, firstly regarding the behavioural intent and willingness to talk to the family and, secondly, regarding signed donor cards. The findings showed that both calculations were reasonable, meaning that the organ donation model may provide a theoretical foundation for further campaigns. Another, more practical finding was that attitudes and behaviours regarding organ donation can be changed by campaigns using both mass media and interpersonal communication. The study concludes with recommendations for general measures and strategies (e.g. "work harder to understand the nature of resistance"<sup>11</sup>) as well as an emphasis on

<sup>10</sup> Horton, Horton (1990), p. 791.

<sup>11</sup> Morgan et al. (2002), p. 271.

the importance of “well-constructed organ donation campaigns”.<sup>12</sup> Schulz et al. (2000) also focused on variables that may predict the willingness and intention to donate organs. Within their study, 134 pupils were tested before and after an educational segment on organ donation. The questionnaire included the topics “knowledge”, “transplantation-specific fears” and “willingness to donate”. These variables were, in turn, linked to various factors including the individual’s trait anxiety, attitude, emotional assessment (meaning) of organ and the frequency of talking about organ donation. The goal of Schulz et al. was to identify the influence of specific factors. They found that “donation-specific fears are predicted by the trait anxiety, the knowledge about organ donation and transplantation, and the emotional meaning of organs”.<sup>13</sup> From that, they deduced that donation-specific fears and the emotional meaning of organs should be considered when planning an effective educational segment.

Other theory-based publications try to examine different psychological effects of communication. Particularly noteworthy are the following: Reinhardt et al. (2007), Hart LaVail et al. (2010), Weber et al. (2006) and Kopfman et al. (1998).

Reinhart et al. (2007) investigated the effect of message framing in the context of organ donation. Whether gain-framed messages or loss-framed messages would generate more positive reactions was first examined. As the results were not conclusive, the relationship between framing and reactions was observed in other ways. In a second trial, message reactions were analysed by using psychological reactance as a mediator for negative reactions. The same was done with perceived manipulative intent in a third study. The suitability of both mediators was confirmed and they were also found to be moderately correlated. As an overall result of Reinhart et al. it can be concluded that gain-framed messages produce more positive message reactions than loss-framed ones as they generate lower levels of psychological reactance and perceived manipulative intent.<sup>14</sup>

Hart LaVail et al. (2010) took up and continued the results of Reinhart et al. as they applied the concept of psychological reactance to an audio-visual public service announcement. In their study, they considered the questions of whether psychological reactance mediates the relationship between perceptions of persuasive strategies and message reactions and whether the effects vary for different donor statuses. Their results indicated that although “...donors experienced perceptions of persuasive techniques and psychological reactance that matched non-donors’ perceptions, such evaluations never acted as significant predictors of message reactions”.<sup>15</sup> In other words, non-donors respond to (negative) message perceptions with a decrease in (positive) message reactions, while donors are not influenced by the same perception.

<sup>12</sup> Morgan et al. (2002), p. 269.

<sup>13</sup> Schulz et al. (2000), p. 64.

<sup>14</sup> Reinhardt et al. (2007), p. 246.

<sup>15</sup> Hart LaVail et al. (2010), p. 62.

Weber et al. (2006) also examined the effectiveness of different messages. By investigating the effects of different contents (statistics and narrative messages) and affects (humorous and sad), they developed an approach for creating persuasive messages. In a first study, they tested the relationship between knowledge, attitude and consent. As the findings indicated that some barriers prevent individuals with a positive attitude from signing donor cards, a second trial was initiated. Within this study, they tested the persuasiveness of different messages in order to advocate donor consent. The main finding of Weber et al. was that narrative messages are preferable to statistics and humorous messages to sad ones.

A comparable study was performed by Kopfman et al. (1998). They examined the cognitive and affective reactions to persuasive health messages when taking prior thoughts and intents into account. One of the primary results was that “statistical evidence messages produced greater results in terms of all the cognitive reactions, while narratives produced greater results for all of the affective reactions”.<sup>16</sup>

Within the category of theory-based publications, the study of Conesa et al. (2003) should also be mentioned as they presented a description of the psychosocial profile of individuals who are in favour of organ donation. In the context of a survey examining attitudes in a Spanish region, they found that the psychosocial profile in favour of organ donation is characterised inter alia by age (up to 40), a high level of education, and experience in prosocial activities. The finding of this study provides information for the future planning of campaigns. A similarly formulated conclusion is made in a study by Yoo, Tian (2011). They examined the effects of TV programmes with organ donation plotlines on people’s attitudes and behavioural intentions (signing a card). One of their major findings was that TV entertainment programmes with a negative framing of organ donation (the most commonly used) have a high ‘miseducating’ impact on those who are sceptical of organ donation. “Since individuals who have not signed a donor card are the main target of organ donation campaigns”,<sup>17</sup> one implication of this result is that campaign messages should try to overcome such myths and misperceptions.

While theory-based publications provide a more comprehensive understanding of the opportunities and limitations to promote a behavioural change, they usually do not offer practical recommendations for campaigning. This role is played by the practice-oriented publications.

<sup>16</sup> Kopfman et al. (1998), p. 279.

<sup>17</sup> Yoo, Tian (2011), p. 150.



### 6.3 PRACTICE-ORIENTED PUBLICATIONS

A highly topical study is presented by Cameron et al. (2013) where they describe and evaluate a Facebook campaign conducted in 2012. In the context of a renovation, “Facebook altered its platform to allow members to specify ‘Organ Donor’ as a part of their profile”.<sup>18</sup> Cameron et al. examined the alteration of registration rates during a four-week period. Therefore, they compared the rates of Facebook status updates and registrations. They found social media-based interventions had a positive influence on the communication of public health problems, which can be explained by the rapid viral distribution among peer networks. Although the presented campaign was directly linked to an online registration platform which, in turn, is linked to specific legislation, its general applicability arises from showing the options for using social media.

Another informative study was conducted by Sanner et al. (1995). They tested different kinds of information regarding their effects on attitudes and the signing of cards. This extensive study was carried out in Sweden, where a certain region was exposed to a broad campaign “including training of different key groups, participation in different meetings and exhibitions, and advertisement of donor cards”.<sup>19</sup> Within the very same region, a brochure was additionally mailed to several households. In another region, households received the brochure only. A control group consisting of the remaining part of the population was also investigated. Sanner et al. found that while the number of card-holders changed significantly in those areas where the brochures had been distributed, a change in attitude was nowhere to be observed. Therefore, they concluded that brochures that are mailed out are the most effective campaigning instrument with regard to making one’s decision official.

Further practice-oriented studies were performed by Matesanz, Garcia et al. (1997), Cameron et al. (2013), Logar Zakrajšek and Avsec (2011), Gäbel and Rehnqvist (1997) and Persijn and van Netten (1997). Examples of actual campaigns are given by Logar Zakrajšek and Avsec (2011), Cossé and Weisenberger (2000), Gäbel and Rehnqvist (1997), Krekula et al. (2009) and Persijn and van Netten (1997). Their contributions describe campaigns that were not carried out in experimental conditions.

Logar Zakrajšek and Avsec (2011), for instance, report about the guidelines developed for organising the “European Donation Day” (EDD) by testing a proposed structure in five countries. Conducted within an EU-funded project, a pre- and post-experimental survey led to the conclusion that a well-organised and structured EDD in combination with intensive and focused work with the media are very effective for distributing information.<sup>20</sup> Cossé and Weisenberger (2000) described a year study referring to a major promotional campaign. They

found that the attitude did not change over the period, whereas the rate of cards being signed increased significantly.<sup>21</sup> Gäbel and Rehnqvist (1997) also described a campaign that was conducted in Sweden. During that campaign, information about new legislation was distributed in different ways (leaflets, advertisements etc.). A pre- and post-experimental survey showed that the campaign was successful in terms of the transmission and perception of the information. Nevertheless, a change in the number of deceased donors could not be observed.<sup>22</sup> Similar findings were obtained by Persijn and van Netten. The authors described an information campaign in the Netherlands that aimed to remove existing misunderstandings and barriers. While the campaign was estimated as being useful, the number of organ donors did not change. This led the authors to conclude that “training and informing the (para-) medical profession and among the management of all hospitals” might turn out to be more effective than campaigns aiming to inform the public.<sup>23</sup> A slightly different approach was taken by Krekula et al. (2009), where a campaign was conducted with the aim to inform the public and create a positive attitude. The authors described two campaigns that were conducted in Sweden. One campaign was a short-term measure in conjunction with the event of a Donation Day. The other campaign was set for the longer term as it lasted almost 2 years. The main finding of Krekula et al. was that the long-term campaign was more effective with regard to knowledge and awareness than the shorter one. Still, none of the campaigns had an actual impact on behaviour.

Independent of campaigns with a focus on day-to-day-communications, Matesanz (2002) gives recommendations for working with the mass media. As the media can at the same time be useful and dangerous, he recommends communicating messages that are “clear, well-defined, positive, and essentially shared by all of those involved in the process”.<sup>24</sup> Further, he recommends sharing such information at periodic meetings where potential misconceptions are openly addressed. Since he highlights the importance of consistent information, he also declares health professionals as the most important group of persons in need of adequate and up-to-date information. This particular focus was also covered in an earlier publication, where Matesanz et al. (1997) stated that health professionals are “prone to be particularly influenced by negative stories in the media”.<sup>25</sup>

Garcia et al. (1997) also focused on the communication with the media. By giving positive and negative examples, they describe the situation as well as problems that occur in communication with the media. On one hand, they emphasise the opportunities through the media but, on the other, they warn against shifting the media’s interest towards “unusual aspects of

<sup>18</sup> Cameron et al. (2013), p. 2059.

<sup>19</sup> Sanner et al. (1995), p. 327.

<sup>20</sup> Logar Zakrajšek, Avsec (2011), p. 35.

<sup>21</sup> Cossé, Weisenberger (2000), p. 297.

<sup>22</sup> Gäbel, Rehnqvist (1997), p. 3093.

<sup>23</sup> Persijn, van Netten (1997), p. 1614.

<sup>24</sup> Matesanz (2002), p. 988.

<sup>25</sup> Matesanz, Miranda (1996), p. 2128.



transplantation”.<sup>26</sup> In order to overcome any problems in communication with the media, in addition they recommend periodic meetings with journalists and media training for spokespersons. They round off their comments by indicating that both transplantation professionals and the media have an obligation to create a positive atmosphere.

## 7 GENERAL RECOMMENDATIONS

Although the selection of the publications referred to above has some limitations regarding its general applicability, several recommendations can still be derived. They can be classified in two types: theoretical recommendations and practical guidelines.

### The theoretical recommendations are:

- **Increase knowledge in order to create a favourable attitude**

Theoretical recommendations for campaigning mainly refer to the variables that constitute the willingness to donate an organ. These variables include inter alia knowledge, attitude, altruism and norms. A major finding of the frequently mentioned experiment of Horton and Horton was “that knowledge is an important variable in the process that leads to the decision to become a potential organ donor”.<sup>27</sup> Thus, an important recommendation for conducting effective communication campaigns is to increase public knowledge. By reducing potential barriers to organ donation (e.g. confusion about brain death, uncertainty about religious support), a more favourable attitude can be created.<sup>28</sup>

- **Effective promotion needs in-depth understanding**

Taking up on the importance of a favourable attitude, Morgan et al. (2002) explain there is a difference between knowledge about organ donation, attitudes, behavioural intents and the actual performance of registering or signing a donor card. Further, they state that successful campaigns need a theory as a foundation. Meeting both claims, the Organ Donation Model (ODM) is introduced.<sup>29</sup> Within the ODM, differences and relations between individual values (knowledge, attitude...) are derived. Another finding of Morgan et al. – also approved within their ODM – is that the influence of a favourable attitude is even greater than the influence of knowledge. For this reason, future campaigns should “work harder to understand the nature of the resistance to organ donation and change those attitudes”.<sup>30</sup>

- **Pay attention to the content and atmosphere**

Weber et al. (2006) investigated persuasive messages. In their study, they found that “humorous messages refuting common organ donation myths are the most effective in increasing consent rates [...]”.<sup>31</sup> In addition, they found that the characters presented in messages/campaigns should be similar to the target audience. The reason stated is that perceptions of similarity can increase personal involvement.

- **Trigger different cognitive and affective reactions**

A more detailed study on how to act on the constituting variables was conducted by Kopfman et al. (2006). They stated that campaigns, or their messages, always trigger cognitive and affective reactions. According to whether messages incorporate mostly statistics or narratives, higher cognitive or affective reactions are caused. This led Kopfman et al. to conclude that messages should include both statistics and narratives, whereby statistics tend to be a little more predominant. Moreover, they stated that the degree of persuasiveness of a message/campaign relies on the prior thought and intent of the individuals involved. Thus, “messages targeted to a high prior thought and intent audience should be most effective”.<sup>32</sup>

- **Highlight the benefits of a behavioural change**

Reinhart et al. (2007) examined in three experiments the effects of message framing on reactions to campaigns. They found that gain-framed messages, i.e. messages highlighting the benefits of a behavioural change, will produce better results than loss-framed messages. Further, they identified psychological reactance, i.e. defence reactions to make a stand against limitations such as psychological pressure, “and perceived manipulative intent as mediators in the relationship between message framing and persuasion”.<sup>33</sup>

- **Do not push**

Hart LaVail et al. (2010) recommended that campaigns communicate implicit appeals, indicating that individuals have the freedom to make their own choices, in order to limit psychological reactance. They also stated that campaigns should be tested in advance to determine how messages are perceived by the audience. This approach can reduce the risk of unanticipated effects.

Along with theoretical recommendations, practical guidelines for campaigning are also given. Amongst others, Feeley, Moon (2009) and Matesanz, Miranda (1996) provide such recommendations.

<sup>26</sup> Garcia et al. (1997), p. 1619.

<sup>27</sup> Horton, Horton (1990), p. 796.

<sup>28</sup> Horton, Horton (1990), p. 799.

<sup>29</sup> Morgan et al. (2002), p. 257.

<sup>30</sup> Morgan et al. (2002), p. 271.

<sup>31</sup> Weber et al. (2006), p. 84.

<sup>32</sup> Kopfman et al. (2006), p. 296.

<sup>33</sup> Reinhart et al. (2007), p. 249.

**The practical guidelines are:**

- **Identify and address your target groups**

Feeley and Moon (2009), for example, stated that knowing the audience is essential for the success of a campaign.<sup>34</sup> Since a 100% reach and a universal perception of organ donation are unattainable, one should take into account specific requirements for communicating with different age, language, religion or ethnic groups. Moreover, Feeley and Moon advised giving clear instructions within a campaign. Instead of only promoting one subject, a campaign should point out the next step (e.g. filling out a donor card, visiting to a dedicated website).

- **The more precisely a target group is characterised, the better is one's knowledge of what will make them pay attention**

Conesa et al. (2003) examined the psychosocial profile of individuals both in favour or against organ donation. They found that “the population subgroup with a negative attitude or one that was not clearly defined toward organ donation was characterised by the following aspects [...] age greater than 40 years old, low educational level, no experience with prosocial activities, a refusal to accept cadaver manipulation or mutilation, and no knowledge of the brain-death concept”.<sup>35</sup> In order to create an effective campaign, Conesa et al. recommended designing campaigns with special regard to this subgroup. A similar finding was made by Krekula et al. (2009). When analysing a short-term and a long-term campaign, they found that, if there was any impact at all, this impact varied substantially between certain subgroups. Accordingly, they recommended a subgroup-specific approach for future campaigns.

- **Involve health professionals at an early stage**

Matesanz and Miranda (1996) gave several recommendations within their publication “Organ donation – the role of the media and of public opinion”. They stated, for instance, that health professionals are the “first and most important group of persons in need of adequate information”.<sup>36</sup> Further on, they emphasised the importance of clear, well-defined and positive messages that are shared by all individuals involved.

- **Use mixed communication channels to reach a broad audience**

In order to reach a wider public and successfully inform about organ donation and transplantation, Logar Zakrajšek and Avsec (2011) found that “TV shows with participating experts, information published in daily newspapers and magazines and documentary TV shows”<sup>37</sup> to be the most preferred channels of communication.

- **Campaigns may support the effectuation**

Sanner et al. (1995) analysed different types of campaigning in three samples and one control group. They found that, although the conducted campaigning did not succeed in changing attitudes towards organ donation and transplantation, they supported the effectuation of one's decision, e.g. signing a card and/or informing the families.

Only a small number of relevant publications (37) questions representativeness.

Most studies were performed in laboratory conditions, with public campaigns seldom being considered. This can be seen as a cause of potential bias.

Despite communication campaigns on organ donation and transplantation being quite common, only a few have so far been evaluated.

However, there are several recommendations to consider when communicating on organ donation and transplantation, such as:

- Increase knowledge in order to create a favourable attitude
- Effective promotion needs in-depth understanding
- Pay attention to the content and atmosphere of a message
- Trigger different cognitive and affective reactions
- Highlight the benefits of a behavioural change
- Do not push the audience
- Identify and address your target groups
- The more precisely a target group is characterised, the better is one's knowledge of what will make them pay attention
- Involve health professionals at an early stage
- Use mixed communication channels to reach a broad audience
- Campaigns may support the effectuation

<sup>34</sup> Feeley, Moon (2009), p. 71.

<sup>35</sup> Conesa et al. (2003), p. 1278.

<sup>36</sup> Matesanz, Miranda (1996), p. 2128.

<sup>37</sup> Logar Zakrajšek, Avsec (2011), p. 35.

**PART III:**

**Communication – The perspective of stakeholders**





The following chapters provide:

- a short presentation of communication models;
- the transition from a unidimensional to a multidimensional model of communication the results of a survey among NCAs regarding their: cooperation with the media; perception regarding the influence of the media; and expectations of FOEDUS WP 7;
- a report on the attendance at the European Commission's 4th Journalist Workshop; and
- a report from journalists concerning their perception of media-related work with national competent authorities.

## 8 BASICS OF COMMUNICATION

Communication plays an important role in any action to inform or educate the general public. For the purpose of this handbook, communication on organ donation between an NCA and the general public via the media will be put in the context of the prevailing models.

### 8.1 THE BASIC MODEL OF COMMUNICATION

Communication is an exchange process that typically involves more than one party (person, organisation etc.) at a time. It describes the transmission of a message from a sender to a receiver. Communication is an instrumental and purposeful process. Since any interaction between two or more individuals automatically implies communication, it can be considered an anticipated, important and conducive process. A simplified model of communication includes three elements: a sender, a receiver and a message (see Figure 19). Within the basic communication model, the sender corresponds to the initiator of the process. The sender produces and transmits a message to the receiver. The receiver, in turn, has to decode and interpret the message.



Figure 19: Basic communication model

Messages can be sent through different channels, depending on the communication purpose, the intended receiver and the type of message. On one end of the channel spectrum there are mass media channels that reach millions of people while, on the other end, there are personalised messages tailored to individuals. Communication channels can be summarised in terms of:

- oral communication, e.g. personal conversation, call, presentations etc.;
- written communication, e.g. personal letters, SMS, information brochures;
- audio-visual communication, e.g. films, radio transmissions; and
- mixed communication.

A transmitted message can be characterised in different ways. For instance, it can be divided into syntactic (signs and symbols), semantic (literal meaning and denotation of signs and symbols) and pragmatic levels (context-dependent meaning).

Communication, furthermore, consists of verbal and non-verbal elements. Verbal communication involves spoken messages; it contains words that were deliberately chosen in order to convey a certain message. Non-verbal communication, on the other hand, is wordless. It is produced by gestures, body language or facial expressions. Non-verbal communication is said to be more rudimentary since it is often used unintentionally. Verbal and non-verbal communication can mutually reinforce and counteract each other at the same time.

In order to effectively communicate to a recipient or target audience, messages should be balanced regarding the previously mentioned characteristics. A message that builds on a misleading or ambiguous syntax, for example, is likely to produce adverse effects. Besides, messages should trigger interest, provide new information, support or help to justify a decision, and be impactful. This process is regarded as successful when a receiver has achieved, acted and responded to a message.

### 8.2 EXTENDED MODEL OF COMMUNICATION

The basic model of communication has to be adapted when focusing on public communication. Here, the receiver is not a single person, but a larger group of people. However, the receiver is also not the general public. There are numerous subgroups which can be defined by different characteristics (e.g. demographic data, media usage, attitude to organ donation) that should be targeted instead. These subgroups play an important role in terms of efficient communication.

Another adaptation relates to the influences public communication processes have been exposed to over the last few decades. Accordingly, the unidirectional model has been replaced by a multidirectional model (see Figure 20). In the new communication model, the receiver is not only a passive observer but also seeks information, develops messages and shares them actively.



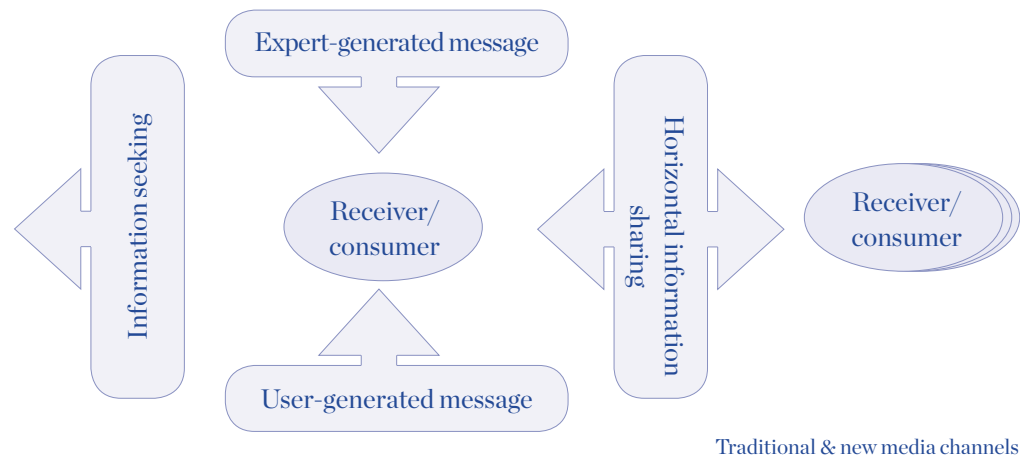


Figure 20: Transition of the basic communication model (adopted from Thackeray, Neiger, 2009)

This new communication model is of particular importance for any public communication measures. Although the receiver (a subgroup of the general public) is still in the centre of the communication process, the emphasis has shifted. Today, the receiver plays a more active role as they can simultaneously be both the receiver and sender/transmitter of a message.

### 8.3 THE OPPORTUNITIES ARISING FROM SOCIAL MEDIA

A major factor necessitating the modified communication model is the development of new communication channels and technologies. Summarised under the broad term ‘new media’, these technologies allow the more rapid and flexible dissemination of information. Examples for new media formats are websites, social media, podcasts and blogs. The most important social networks are Facebook, Twitter, YouTube, LinkedIn, Google+, Instagram, Pinterest etc. with up to 968 million daily active users (for Facebook in 2015).

An essential feature of new media is the provision of information on demand. New media allows access to information at anytime, anywhere and on many different digital devices. Consequently, the former receiver has changed into a consumer, who is not only receiving information but also actively seeking it. Another important characteristic of new media is interactivity. Many formats within new media allow – or even require – the active participation of their users. By creating, sharing or commenting on contents, the receiver/consumer can become actively involved in the communication process or even trigger new processes. Thus, the exceptionally high number of users, the frequency of use (several times a day) and the easiness of distributing information (‘one click’) make social media a useful tool for public communication.

For NCAs, with communication already being an essential part of their day-to-day operations, new media offer numerous opportunities. They enable the fast or even real-time distribution of information as well as great coverage independent of geographical borders. Due to the easiness of sharing messages, status updates and photos with other users (“friends”), the seemingly effortless distribution of information is supported. Consequently, new media offer various options for communicating and mobilising people’s participation in order to develop or support public opinion.

### 8.4 EMERGING CHALLENGES WITH SOCIAL MEDIA

New media, especially social media, are an effective tool for reaching growing numbers of people within a short time. But along with the opportunities, new media also include some risks for NCAs. First and foremost, they are a tool where the sender has little control over the messages and the way they are used and further disseminated. Within new media, content creation is no longer limited to professionals and it is becoming more difficult to distinguish correct from incorrect information. As a result, there is a high risk that false or inaccurate information spread. This effect is even intensified by the fact that any (dis-)information that has been distributed via the Internet can be recalled quickly and at any time.

The increasing availability and quantity of messages via different channels can, moreover, provoke an overload in the receiver. People become more selective in their perception as well as in their response to messages. The outcome is that how information is received, spread and discussed within and across target groups is becoming less predictable for the sender.

The use of social media poses a big challenge for NCAs. While it is an effective and contemporary tool for reaching a mass public, it also requires a lot of attention. Apart from high costs in terms of time and labour, it also requires good and long-term compliance in order to exploit its full potential.

Communication has become increasingly complex due to technical developments and the active participation of the receiver. Today, the receiver not only gets information, but also actively seeks, generates and shares it.

Regardless of the communication channel, NCAs should thoroughly prepare when planning any kind of communication on organ donation and transplantation. They should carefully prepare, analyse and test the intended measures in order to achieve the desired effect.

Committing to new media is a strategic decision that requires a high level of competence and commitment so as to take advantage of all of its potential. Channels should be carefully chosen according to the intended receivers (target group).

### Strengths of social media use:

- high potential
  - large community (~1 billion Facebook users)
  - intermittent reminder: the update of a profile will be visible to all “friends”
- fast update of new information

### Weaknesses of social media use:

- exclusion and non-consideration of ‘non-users’, e.g. people not using/unable to use social media
- data privacy concerns
- it is becoming ever more difficult to differentiate correct from incorrect information
- the web does not forget anything and (dis-)information can always be recalled

### Unsettled questions regarding the use of social media:

- the effect on organ donation rates; and
- an unclear long-term effect

## 9 THE SENDERS’ PERSPECTIVE

WP 7 of the FOEDUS JA aimed to develop a set of recommendations for how to communicate about organ donation and transplantation when talking to the media or general public. Since all NCA representatives communicate with the media as part of their regular activities, it was pivotal to obtain an insight into their experience.

A survey was carried out among FOEDUS partners at the beginning of the action. The objective was to analyse the partners’ experiences and needs in such communication.

### 9.1 METHODOLOGY OF THE RESEARCH ON THE PARTNERS’ EXPERIENCE

A questionnaire was developed in early summer 2013, shortly after the project commenced (see Appendix III). In total, there were 17 questions. Some questions had multiple-choice answers and other questions were open, asking for a short description of an experience or opinion.

The questionnaire contained three sections:

**Media experience:** The first part aimed to provide an overview of the communication activities of each NCA. This part of the survey covered not only information on the frequency of communication, but also aspects related to possible support. Active and passive support

were distinguished, where active means the on-call availability of experts and passive means the provision of specific trainings and/or documents. The survey’s first part also included some questions on the main contents of communication. Besides information on hot topics and topics of general interest, the questions focused on topics and/or addressees that are difficult to deal with.

**Media influence:** The second part of the survey focused on experiences and impressions regarding the effects of positive or negative events and their media coverage. The aim was to create a picture of current opinions on the impact of communication.

**Expectations:** The survey results were used to identify the needs and expectations of the NCAs regarding the work of WP 7. Although the results hold little relevance in terms of developing recommendations for this handbook, a short presentation of the results is given below as they reveal an interesting state of play on the topic in different EU Member States.

Of the 25 associated and collaborating partners and other parties, 19 respondents returned the questionnaire that had been distributed to them by email. This corresponds to a response rate of 76%, which was considered sufficient. Returned questionnaires were reviewed for completeness and subsequently summarised. The participating countries and organisations are: Belgium, Bulgaria, Croatia, the Czech Republic, Eurotransplant, Germany, Greece, Hungary, Italy, Lithuania, Moldova, the Netherlands, Norway, Poland, Romania, Slovenia, Spain, Switzerland and the UK (see Figure 21).

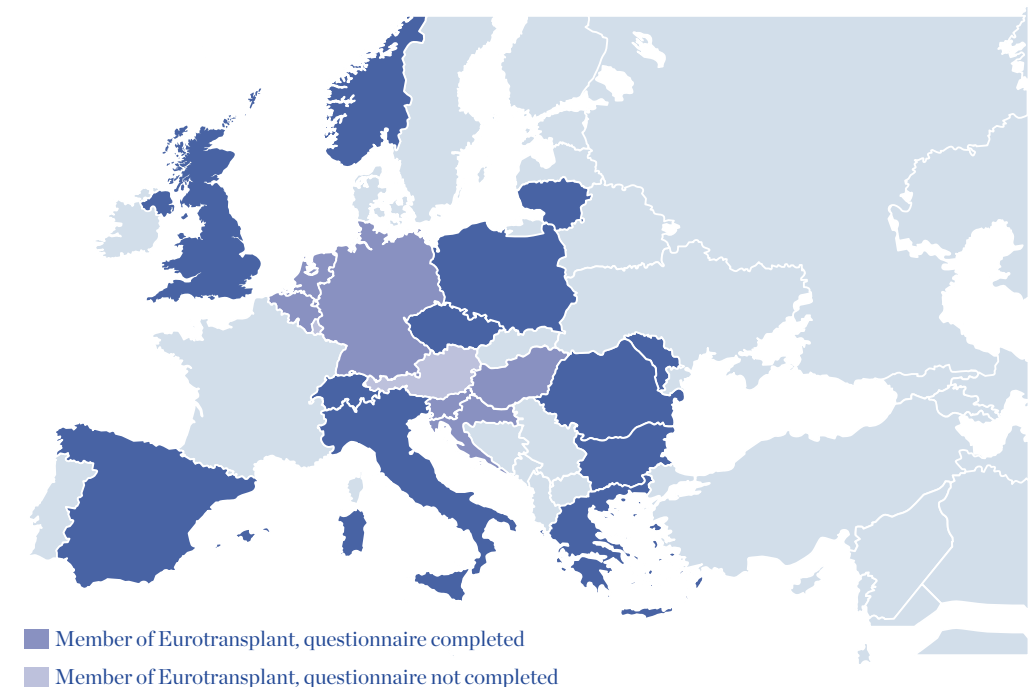


Figure 21: Overview of the respondents

## 9.2 RESULTS OF THE SURVEY AMONGST THE PARTNERS

Before presenting the results, it has to be mentioned that in some European Member States there are several competent authorities at the national level with different responsibilities within the system of organ donation and transplantation. Accordingly, communication activities are sometimes a shared task. For the present survey, no differentiation or subdivision regarding the type of organisation was made. Nevertheless, the need to coordinate not only organ donation and transplantation processes but also communication activities can be seen as an additional complication.

### 9.2.1 MEDIA EXPERIENCE

The first section “media experience” included eight open and closed questions. The questions aimed to obtain an impression on the level of operation and cooperation in communication.

The first question referred to the frequency of media contacts. All respondents stated that they are contacted by the media to talk about organ donation and transplantation at least four times a year (see Figure 22); 12 of the 19 respondents reported having more than 15 media contacts, of which one-third even has 100 and more contacts per year. The frequency of media contacts was analysed to acquire an idea of the extent of communication and consequently of the need for actual/potential support.

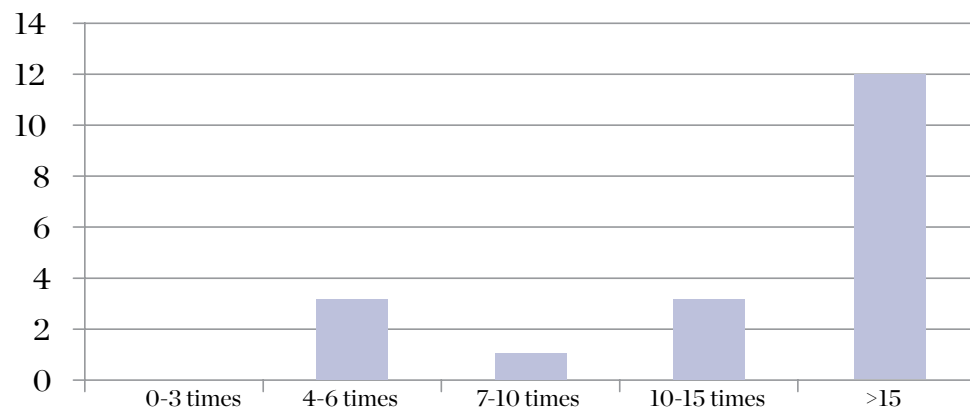


Figure 22: Frequency of media contacts per year

The next question referred to professional assistance when communicating with the media, or for preparing material for the media, where 12 out of the 19 respondents stated they do not receive any on-call support from communication experts. Seven countries have an in-house

public relations department or can receive professional support from an allied institution (e.g. Ministry of Health and/or other delegated bodies). The professional support described by the partners includes contacts with journalists, help in preparing or editing materials for presentations, advice in answering questions or specific help during a crisis.

When asked about previous trainings in the field of public relations, 14 of the 19 respondents reported having received such training or qualification. Although not specific asked for in a question, some respondents extended their answers with recommendations, for example, the need for continuous training that should not only focus on representatives, but also on coordinators, surgeons and other clinicians.

In order to gain an impression of the materials used by NCAs as help when presenting organ donation and transplantation in public, the respondents were asked to name different books, articles, guidelines etc. they consider helpful. Nine respondents stated they had in the past found useful materials such as:

- ‘Guidelines’ written by the Council of Europe, Transplant Procurement Management and ONT;
- Avsec D, Šimenc J (2011) European Donation Day: Toolkit for organisers;
- magazines, the Internet;
- materials distributed at different workshops or trainings where the ‘Spanish model’ was mentioned several times;
- Matesanz R (2008) El Modelo Español de Coordinación de Trasplantes (“the Spanish model”);
- Matesanz R, March JC, Pacini A (2003) Donazioni trapianti e mezzi di comunicazione, Firenze, Semper Ed., 2003; and
- R. Matesanz: Organ Donation, Transplantation and Mass Media. Transplantation Proceedings, 35, 987–989 (2002).

Among the topics frequently requested by the media, most respondents (18/19) stated this to be ‘general aspects’ (‘who can become an organ donor?’, ‘who gets the organs?’ etc.). The second most common answer was ‘life stories of organ recipients or donor families’. Accordingly, 15 out of 19 respondents stated that the personal stories of transplant recipients or organ donor families are a topic of great interest to the media in their countries (see Figure 23).

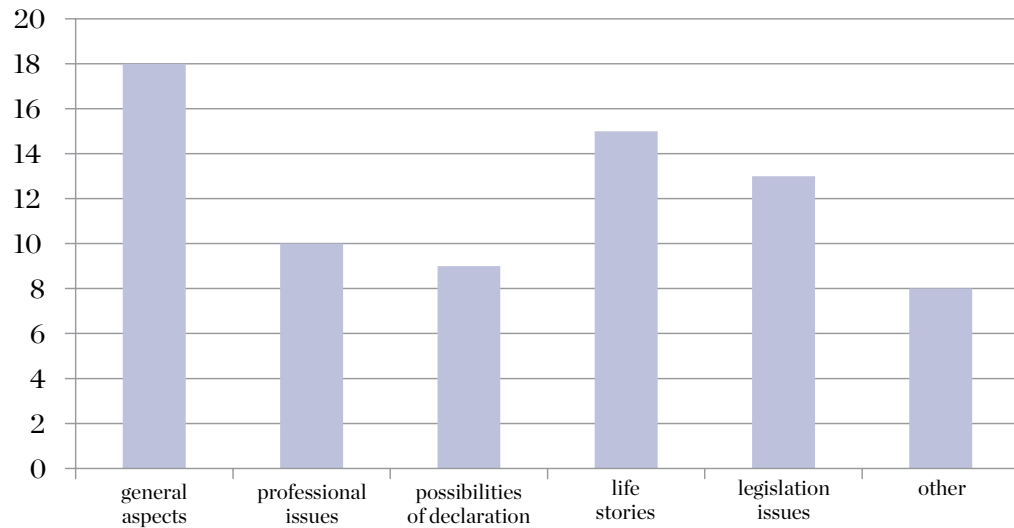


Figure 23: Topics of interest to the media

Interestingly, when asked about topics that are particularly difficult to explain in the media, the majority of respondents (12/19) referred to highly professional issues like aspects of death diagnostics or principles of coordination. Among ‘other topics’, the respondents again listed brain death and donation after circulatory death (3/19) as well as organ trafficking or scandals (3/19). In one case, the communication regarding organ donation and transplantation amongst black and minority ethnic communities was considered to be very difficult (see Figure 24).

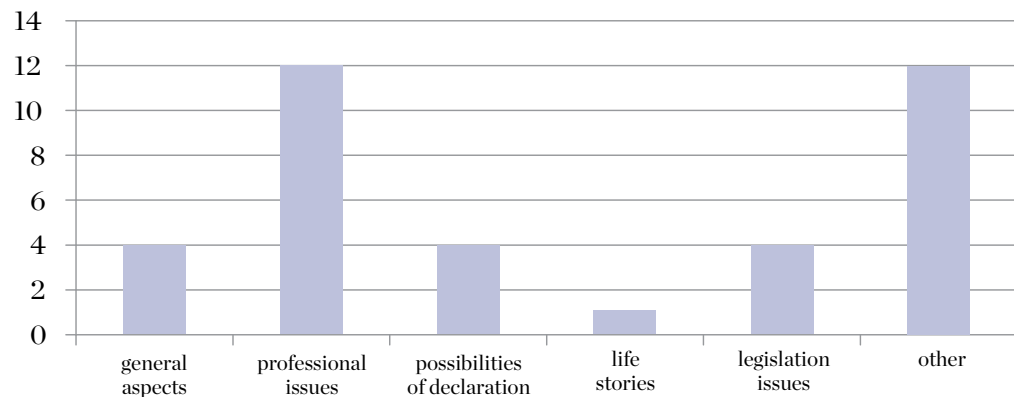


Figure 24: Topics difficult to explain to the media

Media forms regarded as being difficult to communicate with are printed media (magazines and newspapers) as well as Internet forums. For both, 6 out of 19 of the respondents claimed there were difficulties.

The first section ended with questions on possible ‘hot topics’ that had been present in the media in the last few years in the partner’s country; 18 of 19 respondents had dealt with a ‘hot topic’ in the media in the last few years. Among positive topics, the respondents stated: particular life stories, milestones in development of the transplant system, positive results in transplantation activity and similar. Among negative topics, scandals, corruption, manipulation of data and news about organ trafficking were frequently mentioned.

## 9.2.2 MEDIA INFLUENCE

The second section of the survey targeted perceptions regarding media influence, i.e. how NCAs assess the impact of the media on the general perception regarding organ donation and transplantation in their countries. The section included seven open questions.

The first question asked whether any events had been published in the media that, in the opinion of the NCA, influenced the donation rates positively. Corresponding events are, for example, celebrities supporting organ donation and transplantation, stories told by patients and/or donor families etc. In connection with the first question, respondents were asked to provide a short description of the events and an assessment of why they think these events had such an effect. Overall, 18 out of 19 respondents reported on events that, in their opinion, affected the subject of organ donation and transplantation positively.

In Germany, for example, a popular politician donated a kidney to his wife. This resulted in a lot of positive media attention. But, unfortunately, this event did not have any proven effect on donation rates. In the UK, the number of registrations increased after several campaigns regarding the donor register. But the increase in registration rates did not have a direct influence on the donation rate itself. To better illustrate the results, all events were categorised according to their touchpoints, i.e. the approaches taken. The corresponding categories are life stories, campaigns and innovations.

- *Life stories*, for instance, were considered to be positive because they provide “stories that touched the public”. As “people can more easily identify” with real life stories, this “increases awareness”.<sup>38</sup> Hence, 68% (13/18) of the respondents considered that life stories have a positive impact.
- Within the category *campaigns*, the most frequently mentioned events were Donor Days, Marketing Events, Information Programmes, Testimonials etc. The reason for their positive perception is that those events provide “a chance to report on organ donation [...] in a POSITIVE context”. Accordingly, they “help to raise public awareness” and to give

<sup>38</sup> Citations refer to often repeated statements within the survey.



the topic “more credibility”. Campaigns and events were mentioned by 50% (9/18) of the respondents.

- Significant changes in the national transplant system, social media actions, interactive programmes and new ways for the declaration were subsumed under the category *innovations*. This category is considered to have a positive influence because it can provide “added value” to the community. Apart from its actively-supporting character, events in the innovation category are also beneficial in order to reveal a certain topicality (“using social networks is in”). Five respondents claimed a positive perception for events included in this category.

Although almost every respondent could give at least one example of positively perceived events and actions, an actual impact on donation rates could not be evidenced. Apart from normal variations, no significant change or even permanent increase in donation rates was observed that could be related to communications.

Yet the situation was different when the questions were directed towards negative events and their perceptions. Here, 79% of respondents (15/19) provided examples of events that, in their opinion, affected the subject of organ donation and transplantation negatively. Once more, the respondents were asked to describe and assess events and their impact. Again, the results were categorised. The identified areas were criminal actions, critical views of the system and miscommunications/misunderstandings of medical issues.

- Examples for the category *criminal actions* are organ trafficking, organ harvesting manipulations and corruption. Of those respondents who claimed the existence of such events (9/15), 60% provided analogous examples (“people becoming more sceptical”, “...rapidly and negatively influences the audience and that lasts a long time”, “people wonder whether such events could happen in ..., too”).
- In one-third of the cases (5/15), *critics* of the medical/political system or changes in legislation led to a perceived decline in support (“every governmental change is against their existence”, “riot against the law”, “mistrust in the whole system”).
- *Miscommunications/misunderstandings* of medical issues were mentioned in 20% (3/15) of cases (“...information on brain death and permanent vegetative state caused confusion”, “discussions about brain death”).

Regarding the observations of actual changes in donation rates, only 3/15 stated that the events did not have any impact on the donation rates. In the remaining countries, the influence was usually not quantified. Only in a few cases was a measurable decline in donation rates observed, including Germany.

### 9.2.3 EXPECTATIONS

Partners of the FOEDUS Joint Action listed numerous expectations regarding the outcome of WP7. Although all expectations were connected to communication with the media and the general public, some were broad and others were very specific. Partners expected to share and gain knowledge through this Joint Action in order to better communicate different aspects of organ donation and transplantation in public. They would appreciate receiving a tool to ensure a better practice when communicating with the media. Some partners stated that the final goal of such a tool should be informing the public, raising public awareness, and activating people in decision-making. Some expectations also exceeded the framework of this Joint Action like developing a national and international communication strategy, developing common, low-cost campaigns, preventing negative stories or eliminating fraudulent activities.

## 9.3 CONCLUSION

A survey conducted among the FOEDUS consortium at the beginning of the JA reflected an image regarding the level of operation and cooperation in communication. Out of 25 contacted partners, 19 responded to the questionnaire. They had a considerable impact on the strategy of the project. The main findings were:

- NCAs communicate with the media frequently, but only one-third are able to receive any on-call support from communication experts.
- NCAs assess that the media is, besides information on general aspects of organ donation and transplantation and life stories, also interested in negative events like organ trafficking or other scandals.
- The partners find it difficult to explain certain professional issues like brain death, donation after cardiac death, and legal aspects.
- The majority of respondents (18/19) reported on events that, in their opinion, had a positive effect on organ donation and transplantation (life stories, campaigns, innovations). Still, none of these effects was measured in terms of an actual rise in donation rates. In the same context, 15/19 respondents stated that negative press had an adverse effect on the general perception of organ donation and transplantation. And although a precise effect was not quantified, there are countries, such as Germany, where the decline in donation rates can be attributed to negative events.

Important events in the area of organ donation and transplantation are typically followed by media coverage. While positive events can at least be partly initiated (campaigns), they normally do not have a measurable effect on donation rates.

Negatively perceived events and situations, on the other hand, cannot be planned or accurately predicted. But as these events can have a measurable impact on donation rates, a high degree of professionalisation as well as a well-elaborated concept in crisis communication is required.

## 10 THE RECEIVERS' PERSPECTIVE

As the media is considered to be an important multiplier regarding communications in the field of organ donation and transplantation, the following chapter will focus on media representatives, particularly journalists. The knowledge and consideration of each other's backgrounds and interests are considered essential for mutual understanding and smooth cooperation.

### 10.1 JOURNALIST WORKSHOP

In order to gain an insight into the perception, experience and needs of the media when reporting about organ donation and transplantation, representatives of WP7 attended the 4th Journalist Workshop on organ donation and transplantation organised by the European Commission in Brussels on 7 October 2013.

The aim of the annual journalist workshops organised by the European Commission is to provide comprehensive information on organ donation and transplantation to health journalists and to discuss with them the role and expectations of journalists on this topic.

The workshop was attended by 40 participating journalists from different European countries. Speakers were representatives of the European Commission and NCAs as well as organ recipients, living donors and donor families. The topic of organ donation and transplantation was addressed from different angles. Besides general information on organ donation and transplantation, presentations were given on the latest developments, ethical, economic and communication questions. Recipients and donor families shared their life stories and experiences. The discussion among the participants revealed many interesting topics relevant to NCAs.

When asking several media representatives on their assessment regarding the media landscape, they indicated that they face a more complex and competitive situation due to different communication channels with varying requirements ("there is no mass media

anymore!", "nobody gets his information only by reading newspapers or watching news"). In order to sell, the media has to offer a certain added value. In the view of some journalists, this is often mistaken for a sensation-seeking attitude. Moreover, it was pointed out that the need for information depends on the intended communication. For journalists, the key elements of qualitative reporting are:

- **Quick access to information:**

As the number of communication channels and content providers is steadily increasing, time is becoming more and more important.

- **A high level of reliability and validity regarding information:**

Journalists are multipliers between the NCAs and the general public. The information provided to journalists should not differ from the information provided to any other public recipient.

- **The objectiveness, neutrality and transparency of information:**

Objective reporting calls for facts and figures.

On the basis of the information available, it can be noted that communication as well as the media landscape itself are becoming more complex due to the increasing diversity. In order to better cooperate and provide useful information to the media, an NCA should react to the situation. Specific proposals were:

- For journalists, it is always essential to know whom to ask – it is advisable for an NCA to provide a list of contacts who are available 24/7
- Information in terms of facts and figures should be available at any time
- Access to personalised information is perceived better than standardised messages
- New and social media offer a platform to act/react/interact

Using the new communication channels might prove beneficial to all communication partners. Nevertheless, it very important for an NCA to involve experts (e.g. social media experts) already in the developing phase in order to use these communication channels properly.

### 10.2 THE JOURNALISTS' VIEWS

As the media is seen as the key multiplier in the communication with the general public, special attention should be paid to the most important representatives of this group and their perceptions. In the following, an international group of journalists working in the field of health communication provides an exemplary overview of their personal impressions in the field of organ donation and transplantation. The reports below reflect individual opinions of the authors and it is not claimed that they are generally applicable.

It is highly recommended to get in contact with journalists in order to learn about their views and expectations when working in this highly specialised field.

### 10.2.1 DIANA ZAJEC, A SLOVENIAN JOURNALIST

*A journalist's pen is like a surgeon's scalpel*

To be or not to be, to live or not to live – that is not the question. However, many questions and dilemmas surrounding the topic of organ transplantation remain unresolved, even though the unique mission of this branch of medicine is today well known and recognised not only by the medical profession but by the general public.

No matter how accomplished this sophisticated treatment method may be, it cannot quite shake off its attributes of fear, hindrances and anxiety. Although it brings new life to the sick, its activities are also linked to death. Thus, from the point of view of an individual who is healthy and well, dealing with delicate questions such as accepting the interdependence of death and new life, or a discourse on the relationship between the donor and the recipient of an organ, is best postponed to the indefinite future. In most circumstances, a reflection on something as (unpredictably) remote as one's passing on and consequently making a new life possible for other people almost always feels forced and completely unnecessary. Still, as we all know, death is not a clock-watcher. In order to thwart its plans, prompt action is essential. Expert teams experienced in organ transplantation and versed in the art of surgical equilibrium are ready for action 24 hours a day, 7 days a week. The results of their work are breath-taking – in a positive sense. With a new, donated organ, a patient whose quality of life had declined to the minimum, whose life had been hanging by a thread, is awakened into a new existence and given the gift of a new life.

Yet, for all this to be possible, donor organs must be available. The only way to procure them is through an altruistic approach, whereby individuals during their lifetime declare their willingness to donate their organs after they die in order to enable the survival and a happier further life of other people.

In the past, such thinking belonged to the realm of science fiction. Today, it is a reality which has unfortunately not found an adequate response among the public. Although most people admire the achievements of modern transplantation medicine and are strongly in favour of this activity, the prevalent attitude to organ donation after death is still a matter that attracts many doubts.

Therefore, when dealing with this ethically very delicate topic, it is essential that we address our audience (readers) in a subtle, sensitive way. People must not be made to feel uncomfortable while discussing these questions. We must try to arouse in them feelings of self-confidence, a conviction that, by donating their organs once their life has ended, they will be

giving another person a second chance, helping her or him to start a new life. The recipient could be a small boy who needs a new kidney so that he will not spend his life attached to a dialysis machine; a young woman who with a new lung will be able to go on living and bear children; or a middle-aged man with progressive heart failure for whom a new heart will enable him to help his adolescent children overcome obstacles on their life paths ...

Life is unique, no matter how we look at it. It is brief, even if it lasts a hundred years, and relatively unpredictable. Equally unpredictable is its end, in terms of both logistics and time. The possibility for people to save the lives of others by donating their organs when their own life has ended is a major achievement of modern medicine.

People are beings with emotions who are mostly inclined to do good. It is essential that we bring organ transplantation closer to the general public, make it more understandable and more acceptable. The best approach is a balanced combination of the rational and emotional presented in a suitable form. What are most effective are stories of patients whose lives have been saved or dramatically improved by an organ transplant procedure. Such accounts, based on personal experience, are likely to convince even the greatest sceptic.

In this mission, the media plays an important part. A journalist's pen can play an equally vital role as a surgeon's scalpel. It is significantly more effective than any other communication strategy, no matter how carefully thought out. Yet our approach must be correct – frank, sensitive and ethical – showing a profound understanding of the topic and respect for life, for fellow man and for science, which today makes the virtually impossible possible – life after life.

### 10.2.2 MARINA ZOE SAOULIDOU, A GREEK JOURNALIST

Organ donation is characterised by a great variety of ways of thinking as well as different manifestations of fear. As a result, organ donation is not only the outcome of a highly complex altruism, but also one of the greatest challenges for all organisations which are commissioned with the promotion of this excellent idea and caring act. From a journalistic perspective, the reporting of topics related to organ donation is not an easy exercise. It is for this reason that media representatives should try to find a balance between the filtration of events and their coverage. The dimensions of any event should neither be concealed nor misrepresented.

In accordance with the above-mentioned and considering that the distribution of information is not a privilege enjoyed by the media alone, national competent authorities should permit free and unimpeded access to information for relevant editorial offices. This very access to information serves as a foundation for the interaction between a state and its citizens regarding all topics related to organ donation.



Any information flow subject to this matter must be based on transparency rules as well as rules regarding accurateness and punctuality. Hence, messages should be released and provided to the general public before any leakage of information leads to unfounded rumours that result in incomplete assumptions and subjective views.

NCA should seek to build a relationship of trust with the media. This cooperation can be realised by accommodating their needs and organising periodical meetings for an exchange of views and personifying their sources of information.

In addition, NCAs should ensure they communicate clear messages on the objectives regarding organ donation by referring not only to positive events, but also practical difficulties. This sincerity will support the feeling of a common objective. Further, it may serve as a 'cushion' in the event of a crisis.

We should keep in mind that the general public is in need of a guarantee in order to accept the messages provided by a variety of different channels. This offers a way the challenge of communication in the field of organ donation can be successfully mastered for both the general public and NCAs.

### 10.2.3 FELICITAS WITTE, A GERMAN JOURNALIST

#### *'Sex sells'*

*Newspapers want to sell stories that can be sold. Unfortunately, stories with scandals or criticism sell a lot better than stories containing «unemotional» information. By providing serious information and new aspects of transplantation, the excess of «scandalous stories» might be changed.*

From September 2014 to today, 161 articles were published in big German-speaking newspapers about organ donation. Most of them dealt with the scandal about organ donation or blamed politicians, saying that they have to rework the organ donation law. If one reads those articles, he would most probably not feel like donating his organs: The German surgeon Dr. O. in a big university hospital in Germany manipulated the waiting list for organ recipients just to increase his list of operations. At least three people might have died because they were placed further down the waiting list. In other articles, ethicists question: When are we really dead? Journalists discuss whether brain death really means death. A study shows that the risks of a living donation of a kidney are higher than supposed. People try to find a new kidney via Facebook.

'Sex sells': newspapers want to sell stories that can be sold. Unfortunately, stories with scandals or criticism sell a lot better than stories containing 'unemotional' information. When they read such material, it is understandable that people would not like to donate their

organs. I doubt very much if those affecting stories in the yellow press about people who got a new organ and started a new life would increase the will to donate.

When speaking with patients and friends, many did not know much about organ donation and had many unanswered questions. "What happens, when I have an accident, how do the doctors know that I am dead?", "How long do people live with my kidney or my liver?", "I do not want to give my liver to an alcoholic! Can I write in my pass that I do not want to give my liver to them?", "I heard that in Italy medical doctors can take my organs also if I write that I do not want to give them. Is that true?".

Communicating about organ donation is one of the most challenging topics. Newspapers want stories that sell. Organ donation organisations and medical doctors want stories that increase the willingness to give organs. The only way forward entails clear information, transparent communication and new findings. One has to 'appeal to' the editors with their wishes and 'appeal to' the readers with their questions. I would organise a workshop with editors and patients. They could be asked which kind of stories they want to read about organ donation. Which information is missing, which answers are unquestioned.

In my opinion, there is a big gap and a lack of communication between politicians and editors. Politicians want to report what has to be done, that they need more money, more action, more commitment. But editors do not want to write about what has to be done, but about new topics, new aspects of a topic, new studies, 'sexy, attractive' topics. The problem is that organ donation itself is not sexy. So one should find a way to communicate about that topic clearly and comprehensibly. One solution would be to have close contact with editors, invite them to workshops, ask what they want. Transplantation organisations, politicians, medical doctors and all other organ donation experts should be available and willing to answer questions. In workshops with patients, one could identify their questions and how they could be answered. For example, one article in the lay press in the last year wrote about brain death and, although I am a medical doctor, I did not understand it. Another article claimed that the information on the Internet site of the organ transplantation organisation is insufficient or not understandable. As a medical doctor, I always look for interesting studies. There are many studies looking at the quality of life of a patient after organ donation, how long they live and that alcoholic patients after organ transplantation change their life and become abstinent. By communicating those positive stories, maybe one could balance the negative, scaring stories about organ donation scandals. But I rarely get information about these kinds of studies in press releases.

Organ donation in itself is not sexy and will never grab attention like stories about new 'ground-breaking' therapies. If we want to increase the willingness to donate, a first step would be to boost the amount of clear information about organ donation, not only in the lay press, but also in professional journals and on the websites of organ transplantation organisations. We can't change the scandals that happen in daily life. But with good communication we can



'balance the scale' with more clear information that people are not scared. And maybe some of them will change their mind and become willing to donate their organs.

## II SUMMARY AND CONCLUSION

The presentation of the basic model of communication at the beginning of Part III of this handbook served a dual purpose. First, it aimed to further sensitise to the topic of communication. Second, it provided a structure for the following chapters.

The preliminary survey among the partners was an effective tool to assess their experience and needs with media contacts. One notable result was the heterogeneity of the results. Although there is a high overall level of operational experience in communication with the media, there were great disparities between individual NCAs, which is not astonishing when also looking at the size of each NCA, healthcare system and country. Another notable survey outcome was the different perceptions regarding the effects of reporting. While most NCAs stated there are no measurable effects on positive events, there are at least some examples where the publication of negative events was reflected in an actual decline in donation rates. This is remarkable, especially since positive events can be initiated at least in part (information, education, campaigns). However, negatively perceived events cannot even be accurately predicted. In the end, dealing with those events requires a high degree of professionalisation as well as a well-elaborated concept in crisis communication.

Communication inherently involves more than one partner. For that reason, it was deemed essential to obtain an insight into the needs and wants of all communication partners.

Since the media was identified as the most important multiplier in the communication between the NCAs and the general public, an investigation was carried out among media representatives at the European Commission's 4th Journalist Workshop on organ donation and transplantation. The goal was to obtain an impression of how the communication partners work together, including on the European level. Participation at the workshop permitted a thorough discussion of the topic with media representatives. The conclusions supported the previous findings from the survey. NCAs communicate with the media on a frequent basis and should therefore be acquainted with the partners' needs and wants (and vice versa), but still the awareness and understanding between the two communication partners is sometimes limited.

The journalist workshop is considered a positive step forward by offering a regular meeting platform.

Besides the report from the journalist workshop, an even more accurate insight was provided by the media representatives themselves. An international group of three journalists working in the field of health communication presented an exemplary overview of their personal assessments. Although their reports reflect individual opinions, they also support previous conclusions. Improvements in communication are necessary to strengthen the mutual understanding.

Communication must be HOT:

Honest  
Open  
Two-Way.

(Dan Oswald)

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## **PART IV:**

### **Development of messages**



This chapter contains:

- a description of two expert workshops conducted within FOEDUS WP 7; and
- a description of a structured and interdisciplinary approach to developing messages.

## 12 A METHODOLOGY FOR DEVELOPING MESSAGES

In order to realise the development of messages, two expert workshops were conducted. The workshops were attended by representatives of the NCAs as well as external medical and communication experts. Using this approach, two important aspects were fulfilled. On one hand, this approach facilitated the involvement of different relevant disciplines. On the other, it enabled a coordinated operation at the European level. The joint development of a communication concept did not exist in this way before.

### 12.1 PREPARATION PROCESS

The process of message development started with several key lectures on different aspects of communication in organ donation and transplantation under the broader topic of social marketing. The purpose behind this structure was to bring all the participants, e.g. medical experts, PR experts and experts in communication, up to the same level of knowledge. After that, all participants were assigned to four groups according to different subject areas. The subject areas mirrored the general approach of FOEDUS WP 7 with its orientation towards “general information”, information on “cross-border exchange” and “crisis communication” (see Figure 25). As the topic of “general information” appeared to be very broad, it was decided to subdivide it into “organisational aspects” and “medical aspects”. Each group was supervised by a group leader who acted as a coordinator and moderator.

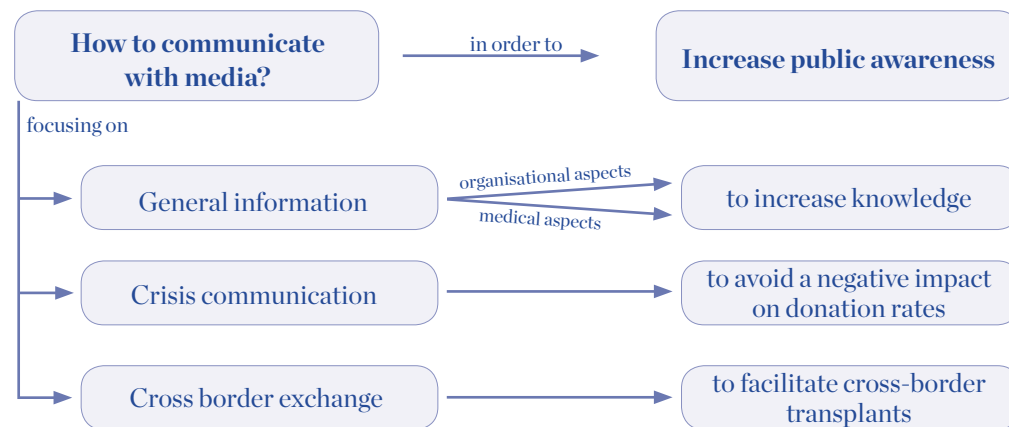


Figure 25: The holistic approach of FOEDUS WP 7

The working group session started with a brainstorming procedure. Participants were asked to name as many topics as possible according to their subject area (see Figure 26). During this step, no limitations were set. Due to the interdisciplinary composition of the working groups, this approach led to extensive outputs.

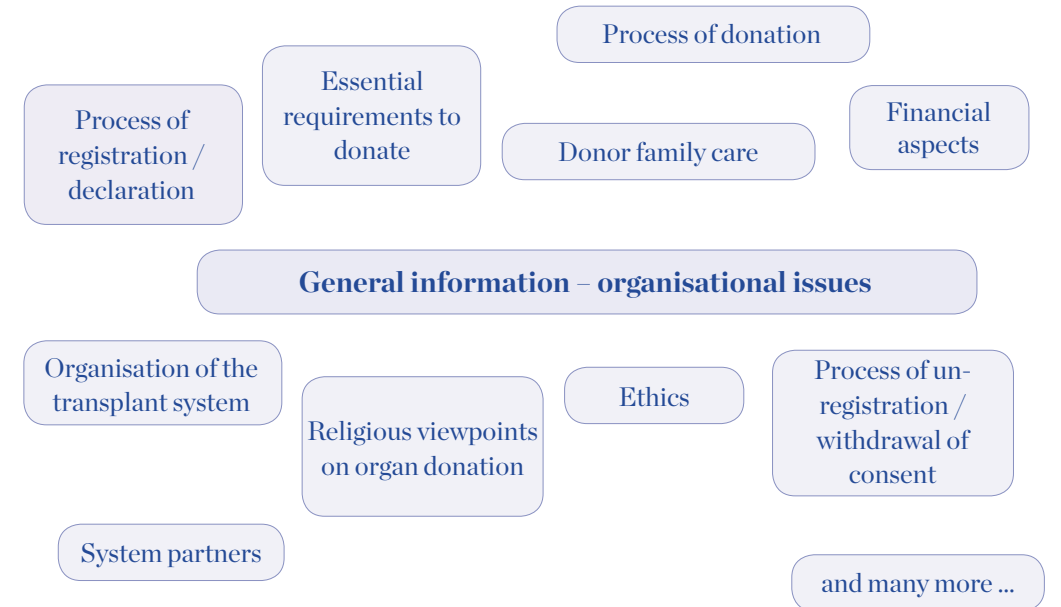


Figure 26: Step 1 - Brainstorming session on subject areas

In the next step, the results of the brainstorming session were reviewed. Each work group was asked to aggregate the results according to superordinate topics and to eliminate potential overlaps (see Figure 27). At the end of this process, every group agreed on a set of relevant topics. These topics provided the basic framework for the subsequent step in message development.

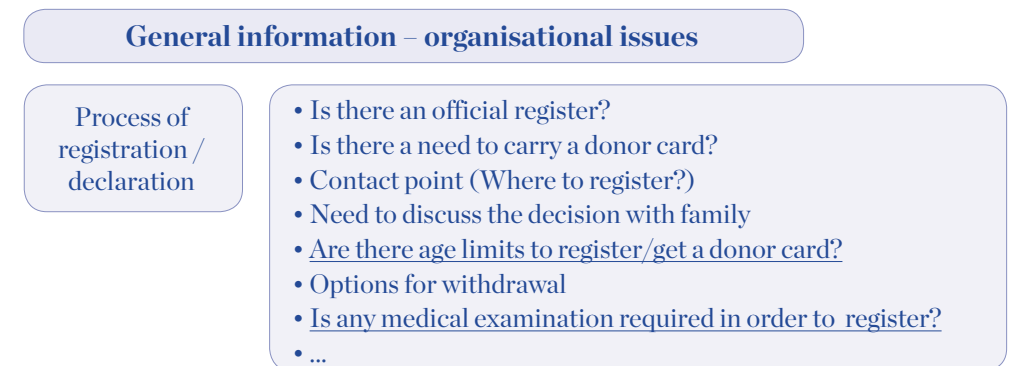


Figure 27: Step 2 - Focus and definition of relevant topics



During this step, numerous topics arose. Each topic was extensively discussed within the interdisciplinary work groups. For selected topics, some aspects were identified as crucial for communications as they constitute basic information on organ donation and transplantation (see Table 5).

Table 5: Selection of topics

General information – organisational issues
<b>Becoming a donor</b>
<b>Expressing one’s decision</b>
Limited/targeted donation
Allocation rules/responsibilities
<b>Family involvement</b>
General information – medical issues
<b>Brain death</b>
Dead-donor rule
Donation after circulatory death
Criteria for high urgent waiting list
<b>Post-transplant results and quality of life</b>
<b>Disfigurement of the body</b>
End of life decision
Usage of organs after euthanasia
<b>Organ trafficking</b>
Crisis communications
In case a crisis occurs due to rules being offended: Admit this is an exception / breach of the rules / common practice / explain the rules and procedures / how this could happen / which measures have been taken / who will be affected
Cross-border exchange and legislation
<b>Definition of cross-border organ exchange</b>
<b>Benefits for cross-border organ exchange</b>
Estimating the increase
Importance for ‘small’ countries
Internal communication
Positive stories
(Selected messages in bold)

## 12.2 DEVELOPMENT PROCESS

When the working groups discussed and agreed on topics they considered relevant for communication, the actual development of messages began.

The aim of this step was to jointly develop clear and objective messages that are easy to understand. The results should be suitable for communication with the general public as well as for discussions with the media.

Similar to the initialisation procedure, the development process was accompanied by an interdisciplinary team of experts. The involvement of medical and communication experts at the same time was important for obtaining clear and explicit messages. Moreover, the active participation of experts from across the FOEDUS participating countries allowed powerful messages to be created that are true for all Member States (see Figure 28).

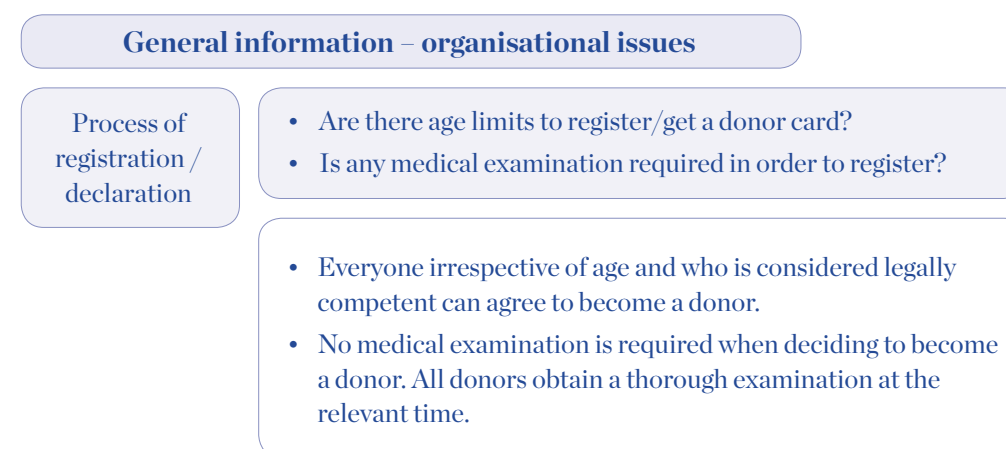


Figure 28: Step 3 – Development of messages

With respect to the great number of subject areas and topics, it was decided to focus on those providing basic information for the general public which also relate to questions frequently asked by the media. In a second step, particular concern was paid to the comprehensibility of messages. The aim was to develop clear and understandable messages for a subsequent test.

## 13 OUTCOMES

After the two workshops, several messages had been developed following an interdisciplinary and international approach. Nine messages were selected as the main outcomes:

1. Everyone can declare their willingness for organ donation.
2. The declaration/decision about organ donation is your personal choice! Inform your families about your personal decision. To make your decision official, you can also use various options, such as your national donor registry or donor card.
3. Families are involved and properly informed before an organ donation takes place.
4. Brain death is the death of a person. It happens when brain functions have irreversibly stopped.
5. Organ transplantation saves lives. For certain diseases organ transplantation is the most efficient or only available medical treatment. After organ transplantation people regain a good quality of normal life.
6. The body of a deceased donor is treated with respect. The procurement of the organs does not lead to disfigurement of the body. An open-casket funeral is possible after organ donation.
7. Organ trafficking is a crime causing exploitation and victimisation. There are several preventive measures, such as organ traceability, at the national and European levels, which protect donors and recipients. National authorities ensure just and transparent organ donation and transplant programmes.
8. Cross-border organ exchange is beneficial for patients within Europe. Cross-border organ exchange enables that every organ procured within Europe will be transplanted. There are several agreements on the exchange of organs donated for transplantation within Europe.
9. The cross-border exchange of organs leads to better results due to optimal matching donor and recipients and shortens the waiting time. Cross-border organ exchange enables us to better treat patients with special needs, e.g. paediatric patients, high-urgent patients.

All messages were translated into the national languages of the five participating countries. The translations were made with the consensus of medical, communication and linguistic experts.

One goal was to develop messages that are true for all Member States, and these messages have quite a broad focus.

**PART V:**

**Messages – Test of effectiveness**



A research agency was engaged to realise the test and provide assistance in the development of a testing methodology. As the test was rolled out in five countries, the agency commissioned its equivalent national offices. All tests were conducted in the national languages and carried out within a couple of weeks in January/February 2015. The participants were first informed about audio recording and data protection measures. The results were submitted in the form of country reports and a final summary report.

The following chapters contain:

- a description of a research model in order to test message effectiveness;
- a presentation of results of a test that was carried out in 5 countries; and
- a discussion of results.

## 14 TESTING METHODOLOGY

A qualitative research model was chosen for the effectiveness test. The background to this decision was to understand what kinds of ideas, opinions, motivations and possible barriers the developed messages could provoke in the general public.

Newton (2011) highlights the significant strength of qualitative research models in their ability to explore the multifaceted, inter-related, private and often conflicting beliefs held by individuals. It allows clarification of what individuals mean and feel when they describe particular beliefs and thoughts.

A qualitative research can be conducted by several techniques, including in-depth interviews. For the present study, the focus group discussion technique was selected. Focus group discussions are moderated and guided group interviews of six to eight people from similar backgrounds. The discussions are interactive and permit participants to talk with each other. Validating the findings from qualitative methods takes more than one focus group on any topic. Qualitative researchers propose three or four focus groups to reach the point of saturation when ideas, opinions and insights repeat (Eliot 2005).

Some limitations of the qualitative approach also exist. Much qualitative research on organ donation and transplantation has been conducted with small samples or among specific target groups. Findings therefore often have limited 'generalisability'. To overcome such a limitation, qualitative findings have often been used to complement the results obtained by quantitative studies (Pope, Mays 1995, Flemming 2007, Morgan et al. 2005). Since this was not within the scope of the present project, it might be a matter for further research.

## 14.1 RESEARCH OBJECTIVES

Nine developed messages focusing on organisational (3 messages), medical (3 messages) and cross-border exchange (3 messages) topics were evaluated according to the following aspects:

- The first objective was to understand whether each message has a clear meaning and whether it sufficiently covers the topic addressed. This objective focused on the rational part of communication.
- The second objective was to understand how the messages should be communicated regarding their context and relevance. This objective focused mainly on the emotional part of communication.

## 14.2 PARTICIPATING COUNTRIES

The test of effectiveness took place in five European countries which differ in terms of their geography, development of transplant medicine, level and quantity of communication and legislative systems. Five EU Member States expressed their willingness to participate in the test: Croatia, Germany, Greece, Hungary and Slovenia (see Figure 29). Although no northern European country was among the participants, the geographical distribution can be considered as balanced. Coincidentally, four of the five countries happened to be members of the European organ exchange organisation Eurotransplant. Since the research focused on the communication of NCAs with the media, this was considered not to cause any significant bias.

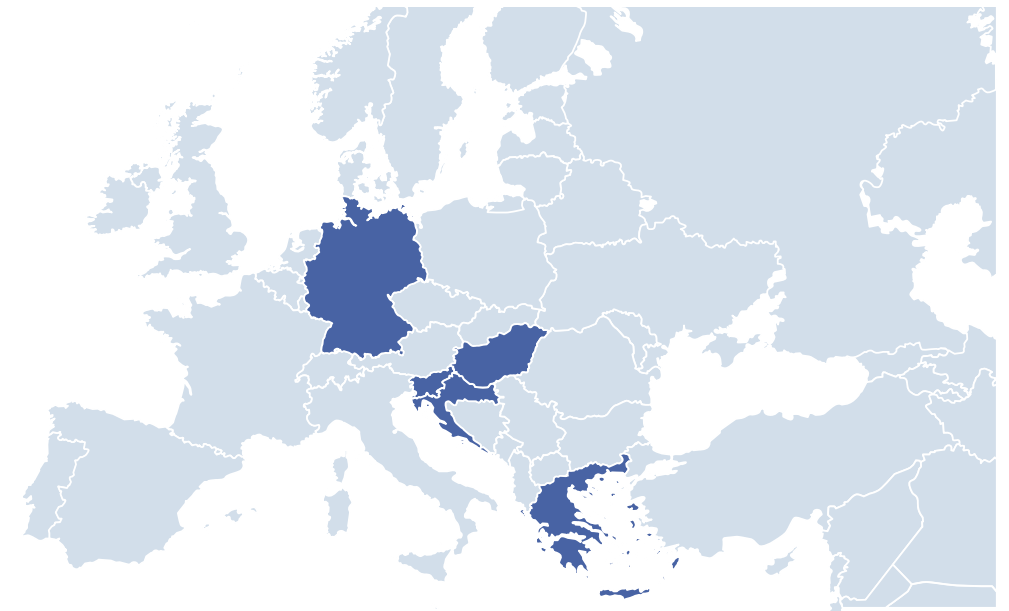


Figure 29: Countries participating in the test of effectiveness



The level and quantity of media communication varies significantly in the participating countries. While some countries stated they have in-house communication departments with more than 30 media contacts per year, other countries specified they neither have an equivalent department nor receive any professional assistance (see Chapter 11). With regard to the development of transplant medicine, including donation rates (donors per million of population) and the legislative system, the participating countries entail a well-balanced mix (see Table 6).

Table 6: Characteristics of the participating countries

	Croatia	Germany	Greece	Hungary	Slovenia
Donor pmp*	33.5	10.7	5.6	15.5	22.9
Consent	Opt-out	Opt-in	Opt-out	Opt-out	Opt-out

\* Deceased donors per million population, 2013; Data from the Council of Europe's Newsletter Transplant 2014

### 14.3 SAMPLE STRUCTURE

The research design involved three focus group discussions per participating country. Each focus group discussion consisted of 6–8 participants. Participants were recruited in a preliminary process to ensure specific composition of the group based on their age, gender, education and attitude to organ donation and transplantation. Two groups consisted of participants undecided about organ donation. These two groups differed in their age. One group included people aged from 18–40 years, while the other group included people from 41–70 years. The third group included people who declare themselves as organ donors. This group had mixed ages (see Table 7). The recruitment process ended with 120 respondents (23+24+24+25) who participated in the effectiveness test.

Table 7: Target composition of each country's focus groups

	Focus Group 1	Focus Group 2	Focus Group 3
Attitude towards OD	Undecided	Undecided	Decided
Age	50% 18–30 y 50% 31–40 y	25% 41–50 y 25% 51–60 y 50% 61–70 y	50% 18–30 y 50% 31–40 y
Level of education	25% low 50% middle 25% high		
Gender	50% female 50% male		

The selected structure of the groups intended to gain an understanding of whether the groups had a different perception by way of attention-raising, cognitive and emotional responses to the messages.

### 14.4 TESTING PROCEDURE

Focus group discussions are structured around a set of carefully predetermined questions known as 'discussion guide' – but the discussion is free-flowing. The discussion guide is a semi-structured questionnaire consisting of subtopics relevant to the research objectives. The moderator's goal is to generate the maximum number of different ideas and opinions from as many people as possible.

Each focus group discussion started by introducing the participants, followed by a session where the participants shared their initial ideas, feelings and thoughts about organ donation and transplantation. A reason for this warming-up exercise was to obtain the respondents' spontaneous associations on the topic. After the introductory session, pretesting of the messages was carried out. Respondents individually filled in a short questionnaire (individual protocol) about the developed messages. The tested messages were presented in three sections (medical, organisational, cross-border exchange). The evaluation of the messages followed a three-step approach:

- The first evaluation referred to the respondents' individual perception of the message. Using a colouring exercise, the participants highlighted each word in green colour to indicate important/favourable/relevant information. Red colour indicated unclear/non-relevant information of the message.
- In the second step, every message was assessed according to six dimensions (favourable reaction, catching attention, relevant, clear, includes all important information, tells something new) using a four-point scale ranging from strongly agree to strongly disagree (see Appendix IV).
- In the third step, every message was discussed within the group. The moderator monitored the flow of the discussion and steered the group's attention to the following aspects: initial associations, clarity of the message, newness, completeness, importance of certain information.

After discussing all sections of the messages, a post-testing assessment of the messages was carried out. Individual protocol questionnaires were redistributed to check whether the discussion had led to any change in attitude. The focus groups ended with an overall evaluation.

## 14.5 QUALITATIVE ANALYSIS

The qualitative analysis entailed these four steps:

1. Verbatim transcript of the audiotaped discussion.
2. Organising transcripts pertaining to each message into subtopics, identifying common categories or themes for each message.
3. Analysing subtopics, identifying similarities and differences among participants and among groups.
4. Synthesising meanings, naming sub-category heading titles, summarising the findings for each subtopic, noting similarities/differences.

The colouring exercise from the individual protocols was analysed by counting the red and green underlined words. Based on the frequency of the coloured words, the font size of the word was assigned in the results section. Bigger fonts mean significant and important words. Some words had dual perceptions – certain participants found them important/understandable while others perceived them as not important/not complete. In such cases, another colour (blue) was used to indicate the words/phrases with a mixed perception.

## 15 TEST RESULTS

The nine messages were tested and analysed in terms of general perception as well as group perception (decided/undecided) about organ donation. The number of results for the effectiveness test was extensive. For the purpose of this handbook, it was decided to present the results in a condensed and practically oriented way, ready for further use in communication with the media or the public. The results can be divided into country-specific and comparative results. Only comparative results representative of the participating countries are presented here. The results of the individual questionnaires for evaluating the messages are not presented here since they only served as a supplementary instrument for the qualitative analysis.

### 15.1 ORGANISATIONAL MESSAGES

Three messages were developed and chosen for the effectiveness test from the organisational part of organ donation activity. These are:

1. Everyone can declare their willingness for organ donation.
2. The declaration/decision about organ donation is your personal choice. Inform your families about your personal decision. To make your decision official, you can also use various options, such as your national donor registry or a donor card.
3. Families are involved and properly informed before an organ donation takes place.

Key points: The three organisational messages are perceived as an introduction to the organ donation topic. They are particularly important for undecided people in countries with less knowledge (Hungary, Greece). The section of short and simple organisational messages raises the importance of organ donation and gives motivation to act. Nevertheless, this section needs additional information or it could be perceived as trivial.

#### 1st Message:

**Everyone can declare their willingness for organ donation.**

Table 8: Colouring exercise: Message 1

Undecided groups	Decided groups
<p>Everyone can declare their willingness on organ donation.</p>	<p>Everyone can declare their willingness on organ donation.</p>
<p>Green: Relevant/important/favourable information            Red: Unclear/non-relevant information            Blue: Words/phrases with mixed perceptions            Font size: According to the frequency of the colourings</p>	

#### General perception

In general, the participants accept this message as relevant and comprehensible. Moreover, the message is perceived as attractive because it is short and easy to remember. The first exposure to the message in all countries showed the lack of context. Only later in the second exposure, when the participants had already received broader information, did the first message become more relevant and clear.

#### Threats to comprehensibility

The word “everyone” has mixed perceptions because it invites every person and does not make any difference – young/old, healthy/with comorbidities. This completeness was often doubted later in the discussion.

The second threat was perceived with the word “declare” by which the decision to become a donor sounds final and conclusive. Participants would prefer this first message to appear more inviting. In all countries the word “declare” was deemed formal and would therefore not fit into the emotional meaning of the message. It was important for the participants that the message does not push for a decision to become a donor. It should instead invite people to take a decision that can be evaluated and declared later.

## Exceptions

The participants in Greece perceived this message as vague and relatively incomplete (all participants stated that they need to connect this message to the 2nd message). The participants in Hungary (particularly undecided) revealed a lack of knowledge as it was not clear to them whether the message refers to a living or a deceased donation.

## How to communicate

The first message communicates on two levels: generally, it is perceived as a driver, the opening information, which conveys a positive and actionable intention in society. On the other hand, it also refers to the intimate and personal level.

When using such a message, it is important to stress that the decision-making process is not an obligatory and one-off action (“It is an opportunity not an obligatory action”). The emotional dimension of the topic has to be respected as it may function as a cushion between fear of making a serious decision and being altruistic. The first message needs to include an optimistic tone since it is the personal freedom of choice, although it implicitly refers to an individual’s responsibility to be altruistic.

While important, the emotional appeal alone is not enough because the decisions also need to be taken on a rational basis. Therefore, more rational and functional information is needed in the continuation of the message: who can be a donor (e.g. age limitations, health conditions), how to declare the decision (e.g. registry, donor card, informing family), where to declare the decision, and why it is important to declare one’s decision.

Table 9: Strengths and weaknesses: Message 1

Strengths	Weaknesses
<ul style="list-style-type: none"> <li>• Short and comprehensible</li> <li>• Perceived as a slogan, an invitation or an opening message</li> <li>• Driver for more information</li> <li>• Functional: relevant to decided and undecided people</li> <li>• Emotional: free will and possibility to choose, emphasises the personal decision (not a decision of someone else, institution, government)</li> <li>• Draws attention to the importance of the topic</li> </ul>	<ul style="list-style-type: none"> <li>• The message alone has no communication power and needs a broader context</li> <li>• Vague words: “everyone”</li> <li>• Words with a formal tone: “to declare”</li> </ul>

## 2nd Message:

**The declaration/decision about organ donation is your personal choice. Inform your families about your personal decision. To make your decision official, you can also use various options, such as your national donor registry or a donor card.**

Table 10: Colouring exercise: Message 2

Undecided groups	Decided groups
<p>The declaration/<b>decision</b> about organ donation is <b>your personal choice</b>. Inform your families about your personal decision. To make your decision <b>official</b>, you can also use various options, such as your <b>national donor registry or a donor card</b>.</p>	<p>The <b>declaration/decision</b> about organ donation is <b>your personal choice</b>. Inform your families about your personal decision. To make your decision <b>official</b>, you can also use various options, such as your national donor registry or a donor card.</p>
<p>Green: Relevant/important/favourable information            Red: Unclear/non-relevant information            Blue: Words/phrases with mixed perceptions            Font size: According to the frequency of the colourings</p>	

## General perception

This message is perceived as a logical continuance of the 1st message – it more straightforwardly promotes the ‘personal’ dimension of decision-making. In all countries, the message evokes a positive perception as it is transparent and emphasises the complexity of being an organ donor. The message contains three pieces of important information:

- Personal decision (=emotional)
- Closest people need to be involved (=emotional)
- Organisational aspect regarding declaration (rational)

## Threats to comprehensibility

A personal decision is intimate and individual. The role of ‘close people’ is not clearly defined and therefore evokes doubts about the extent of this personal autonomy.

Second, ‘to make your decision official’ differed according to each country’s legislative framework. People need to be properly educated about the system before declaring their organ donation decision (Hungary, Greece and Croatia).



### Exceptions

There were no specific differences in the perception of this message among the countries, but it should be emphasised that slight adaptations were made when translating this message into the participating countries' national languages due to different declaration options.

### How to communicate

The message is overall important and relevant, particularly for undecided participants. It can be joined with the first message.

'Personal decision' has emotional connotations as it reveals that every individual needs to decide by himself. Still, individuals need to be conscious and inform those who are close to them in order to avoid burdening them in the case of a potential organ donation. From a rational aspect, a corresponding communication is needed:

- why the decision is personal and who has to be involved and to what extent
- practices regarding informing and involving family members/closest persons in the relevant country according to their practice
- 'info corner': where, when and how to declare a decision:
  - why is it important to make our decision official
  - what does it mean that a decision is official/formal?

A lot of attention should be paid to designing the tone of communication because each subtopic requires a different tone.

The description of 'family' seems too narrow. Here, it is necessary to better define who should be informed about the decision since some other close person could be equally important.

Table 11: Strengths and weaknesses: Message 2

Strengths	Weaknesses
<ul style="list-style-type: none"> <li>• Involving the closest people – important stakeholders in the decision-making process</li> <li>• New information</li> <li>• Direct proposal: how to decide and come to a realisation about the decision</li> </ul>	<ul style="list-style-type: none"> <li>• Lack of information about the involvement of family members</li> <li>• The message requires a certain degree of knowledge regarding the legislative framework</li> <li>• The combination of three subtopics requiring different tones of communication is difficult to address</li> <li>• The words "declaration" and "official" have a bureaucratic connotation</li> </ul>

### 3rd Message:

**Families are involved and properly informed before an organ donation takes place.**

Table 12: Colouring exercise: Message 3

Undecided groups	Decided groups
<p><b>Families are involved and properly informed before an organ donation takes place.</b></p>	<p><b>Families are involved and properly informed before an organ donation takes place.</b></p>
<p>Green: Relevant/important/favourable information                      Red: Unclear/non-relevant information                      Blue: Words/phrases with mixed perceptions                      Font size: According to the frequency of the colourings</p>	

### General perception

The third message revealed some comprehensibility issues in all countries. Family members were sometimes understood as being the final decision-makers with the opportunity to act against the expressed will of the deceased, which gives the previous messages questionable relevance. Participants perceived the message according to the following aspects:

- target group: each person has a possible double role in the organ donation process:
  - to decide for oneself as a potential donor, or
  - to be involved in an organ donation discussion as a relative (which is mainly perceived here)
- the target group's needs:
  - undecided: the message is relevant to them because they need an approval for their personal decision – family/close people could give this
  - decided: disapprove the message since they have already gone through the entire intimate decision-making process.

### Threats to comprehensibility

The message in its current form opens up too many aspects. Nevertheless, the inclusion of the family is important in all countries from both cultural and individual points of view.

### Exceptions

Hungary is the country where a lack of information regarding organ donation practice and declaration options was the most obvious in the focus group discussions. Therefore, subtopics like the role of family members in the decision-making process were perceived as too complicated and confusing since the participants were not competent about the basics.



Greek participants, on the other hand, stressed that the family is particularly important in this context. Therefore, this message reflects for them an ethically respectful and a transparent system (if the family is involved – the system is transparent, well organised, nothing is hidden).

Germany: undecided participants preferred this message since it defines the role of the family in organ donation.

### How to communicate

This message could be a continuation of the second message, but it needs to contain additional information about the extent and decision power of family members. Some additional facts could be covered:

- Timing: “When is the information process taking place?”
- Responsibility: “Who is talking to families?”

Communication should comply with the accepted role of the family in the cultural discourse. Although family matters are always emotional, there is a need for objective information that is clear and could reduce anxiety about becoming/being an organ donor.

Table 13: Strengths and weaknesses: Message 3

Strengths	Weaknesses
<ul style="list-style-type: none"> <li>• Shows that inclusion of the family in the organ donation process is important</li> </ul>	<ul style="list-style-type: none"> <li>• Incomplete information about families: who/when/how/what exactly?</li> <li>• Confusion: personal choice vs. family members as final decision-makers</li> <li>• Emotional burden might occur for the family</li> <li>• Unclear words: “involvement” and “properly”</li> <li>• Definition of ‘family’ – closest persons or family members?</li> <li>• Is family involvement a ‘must’ or a ‘nice to have’ step?</li> </ul>

## 15.2 MEDICAL MESSAGES

In the section of the messages from the medical aspect of organ donation, the following messages were analysed:

4. Brain death is the death of a person. It happens when brain functions have irreversibly stopped.
5. Organ transplantation saves lives. For certain diseases, organ transplantation is the most efficient or only available medical treatment. After organ transplantation, people regain a good quality of normal life.
6. The body of a deceased donor is treated with respect. The procurement of the organs does not lead to disfigurement of the body. An open-casket funeral is possible after organ donation.

Key points: Messages about medical aspects are perceived as an educational section and as very important due to their potential to reduce the barriers. Introducing facts in this section supports the cognitive level of the decision-making process. The messages are informative and offer the possibility to decrease the lack of knowledge about medical aspects, particularly among undecided groups.

### 4th Message:

**Brain death is the death of a person. It happens when brain functions have irreversibly stopped.**

Table 14: Colouring exercise: Message 4

Undecided groups	Decided groups
<p><b>Brain death is the death of a person.</b> It happens when <b>brain functions have irreversibly</b> stopped.</p>	<p><b>Brain death is the death of a person.</b> It happens when brain functions have <b>irreversibly</b> stopped.</p>
<p>Green: Relevant/important/favourable information            Red: Unclear/non-relevant information            Blue: Words/phrases with mixed perceptions            Font size: According to the frequency of the colourings</p>	

### General perception

On an individual level, death evokes existential considerations. A topic that is provocative for everyone, death also represents a strong social taboo. Considering this, reflecting on death is not often present in everyday life. It recalls issues such as the end of human life. Further, the medical term of brain death opens some doubts and attracts controversy in general. It has raised scepticism of medical procedures and professionals. The message about brain death has a stronger influence on undecided groups while decided groups also need evidence that their decision has been based on credible knowledge about brain death.

The fourth message, although sometimes perceived as shocking, is acknowledged as very important even though it does not offer complete answers. The key word in the message is “irreversible”, which leaves little doubt regarding a person ‘coming back to life’.

### Threats to comprehensibility

In this message, brain death is not further explained or put into a broader context. Hence, the participants asked why a discussion about a certain kind of death is needed at all. The uncomfortable feeling the topic evoked among several participants raised the need for more objective information (how, who can define brain death).

Use of the medical term triggered the impression of a cold and technical communication tone.

### Exceptions

Croatia is the country where death was perceived as the most frightening topic and the evaluation of this message evoked the most negative perceptions due to its difficult emotional processing.

### How to communicate

It is recommended to add the following information in the communication about brain death:

- Brain death is the only/most frequent possibility to perform organ donation post mortem
- A clear difference from a comatose state
- A broader explanation of how and when it is diagnosed
- Who is responsible for the identification of brain death

The message about brain death is important and relevant, but needs to be communicated with full sensitivity. Messages about brain death are not appropriate as starting messages. They should be communicated after the audience has already received an introduction to the topic.

Spokespersons should be medical doctors who are also familiar with other aspects related to brain death, such as spiritual aspects and reflections about life after death. These aspects should be treated with great sensitivity.

Table 15: Strengths and weaknesses: Message 4

Strengths	Weaknesses
<ul style="list-style-type: none"> <li>• Openly addresses the topic of ‘death’</li> </ul>	<ul style="list-style-type: none"> <li>• Provokes the deepest fear</li> <li>• Relevance to organ donation is unclear</li> <li>• The word “irreversible” can provoke either trust or doubt</li> </ul>

### 5th Message:

**Organ transplantation saves lives. For certain diseases, organ transplantation is the most efficient or only available medical treatment. After organ transplantation, people regain a good quality of normal life.**

Table 16: Colouring exercise: Message 5

Undecided groups	Decided groups
<p><b>Organ transplantation saves lives.</b> For certain diseases, organ transplantation is the most efficient or only available medical treatment. After organ transplantation, people regain a good quality of normal life.</p>	<p><b>Organ transplantation saves lives.</b> For certain diseases, organ transplantation is the most efficient or only available medical treatment. After organ transplantation, people regain a good quality of normal life.</p>
<p>Green: Relevant/important/favourable information            Red: Unclear/non-relevant information            Blue: Words/phrases with mixed perceptions            Font size: According to the frequency of the colourings</p>	

### General perception

Among all the messages that were evaluated, this was the most appealing, important and relevant in all countries. Its major strength is the explicit and clear presentation of the benefits for two stakeholders:

- Organ donor: the highest stage of altruism
- Organ receiver: the message refers to the value of organ donation from the receiver’s point of view.

The following key points highlighted the importance of the message:

- ‘Saving lives’ is a phrase that is considered a definite leader, also with the insight of saving several lives, not just one;
- ‘Regain a good quality of life’ refers to the final result, similar to giving birth, the most precious act of a human being;
- ‘Reciprocity effect’ (“There are many chronic diseases – maybe one time, I, as a potential organ donor, will need an organ too”).

### Threats to comprehensibility

Two parts triggered certain doubts:

- The phrase ‘regain a good quality of normal life’ implies a certain risk because it leaves an option of not regaining a good quality of life. It may also be perceived as exaggerated or unrealistic; organ transplantation is not always successful.
- If something is called ‘most efficient’, it does not allow space for questioning a different opinion, which could evoke scepticism in countries with recent scandals.

### Exceptions

The German participants (especially undecided elders) were more sceptical, especially with regard to the last sentence about regaining a good quality of life. In addition, decided people argued that this message has a strong promotional appeal which sounds unrealistic. By mentioning that organ donation is the ‘only treatment for certain diseases’, some decided participants in Germany further feared that this might be perceived by undecided people as forcing towards donation. It is worth noting that this was not the case for the majority of undecided German participants.

### How to communicate

The first sentence of the message is indisputably relevant and important for all:

- Undecided: need to present the positive, core advantage of being an organ donor and eliminate the deepest fears;
- Decided: need to continuously repeat that they have made a good decision, ‘this is why we are doing it’.

Related to this topic, the following questions might also be addressed:

- Which are those ‘certain diseases’?
- What does it mean that this treatment is the ‘most efficient’/‘only available’?

Table 17: Strengths and weaknesses: Message 5

Strengths	Weaknesses
<ul style="list-style-type: none"> <li>• The core principle of donation is highlighted: saving lives</li> <li>• Relevant in a positive way for decided donors, receivers, families</li> </ul>	<ul style="list-style-type: none"> <li>• The use of superlatives gives a tone of communication which is too promotional (e.g. the most, only available, good quality)</li> <li>• Unclear: certain diseases, only/the most efficient treatment</li> </ul>

### 6th Message

**The body of a deceased donor is treated with respect. The procurement of the organs does not lead to disfigurement of the body. An open-casket funeral is possible after organ donation.**

Table 18: Colouring exercise: Message 6

Undecided groups	Decided groups
<p><b>The body of a deceased donor is treated with respect.</b> The procurement of the organs <b>does not lead to disfigurement of the body.</b> An <b>open-casket funeral is possible after organ donation.</b></p>	<p><b>The body of a deceased donor is treated with respect.</b> The procurement of the organs <b>does not lead to disfigurement of the body.</b> An <b>open-casket funeral is possible after organ donation.</b></p>
<p>Green: Relevant/important/favourable information            Red: Unclear/non-relevant information            Blue: Words/phrases with mixed perceptions            Font size: According to the frequency of the colourings</p>	

### General perception

Funerals are an important rite of passage. Having this information in mind, this message is addressing two stakeholders:

- the bereaved family: to gain more confidence in the process of procurement
- the organ donor: perception of their own body.

This message is more informative from the perspective of a donor’s family and religious people. The message is also important for undecided persons since it can contribute to actualising the decision about organ donation (especially in countries where the opinion of

the family is appreciated). In the focus group discussions, age had a significant effect on the perception of this message: older participants (especially outside urban places) are more likely to follow traditional rituals and therefore this message is more relevant for them (as mentioned by the Greek and Hungarian participants).

#### Threats to comprehensibility

“Respect” as the key word in this message needs further explanation because it signifies it is to be gained by certain actions. The word “dignity” was proposed as an alternative (Germany, Croatia).

#### Exceptions

In every country, funerals depend on cultural rituals. Special attention should be paid to the perception of funerals in urban or rural places. In Germany and Greece for instance, open-casket funerals are not common or even not possible; in Athens, the body of the deceased is exposed (if at all) only for a few minutes, whereas the only visible part is the face and the rest of the body is usually covered with flowers. In Germany, undecided participants expressed doubts and insecurity upon the mention of “disfigurement” and the ‘possibility of normal funeral procedures’, as this is usually taken for granted.

#### How to communicate

This message should be communicated with special sensitivity as it delivers three important pieces of information:

- there is no disfigurement of the body;
- dignity is ensured during organ procurement; and
- all funeral practices are possible.

Table 19: Strengths and weaknesses: Message 6

Strengths	Weaknesses
<ul style="list-style-type: none"> <li>• Understandable</li> <li>• Stresses that during organ procurement the body is treated respectfully</li> </ul>	<ul style="list-style-type: none"> <li>• The word “respect” has a connotation which is too wide – respect is gained by certain actions. The word “dignity” was proposed as an alternative (Germany, Croatia).</li> </ul>

### 15.3 MESSAGES ABOUT CROSS-BORDER EXCHANGE

In the cross-border organ exchange section, the following messages were analysed:

7. Organ trafficking is a crime causing exploitation and victimisation. There are several preventive measures, such as organ traceability, at the national and European levels, which protect donors and recipients. National authorities ensure a just and transparent organ donation and transplant programmes.
8. Cross-border organ exchange is beneficial for patients within Europe. Cross-border organ exchange enables every organ procured within Europe to be transplanted. There are several agreements on the exchange of organs donated for transplantation within Europe.
9. The cross-border exchange of organs leads to better results due to optimal matching between donor and recipients and a shortening of the waiting time. Cross-border organ exchange enables us to better treat patients with special needs, e.g. paediatric patients, high-urgent patients.

Key points: The concept of cross-border organ exchange adds new information that is positive and supportive of organ donation since it directly emphasises better results due to the possibilities of every organ to be used. Detailed information about the exchange process needs to be clarified in continuing the communication to reduce fears and barriers. The first information satisfies the need to be aware of a clear benefit, but details should meet the need for more profound knowledge, especially for decided people. Medical or law professionals with credibility should be the main spokespersons. The message about organ trafficking (7th) is perceived to be threatening because negative aspects of organ donation are mentioned.



## 7th Message

**Organ trafficking is a crime causing exploitation and victimisation. There are several preventive measures, such as organ traceability, at the national and European levels, which protect donors and recipients. National authorities ensure a just and transparent organ donation and transplant programmes.**

Table 20: Colouring exercise: Message 7

Undecided groups	Decided groups
<p><b>Organ trafficking is a crime</b> causing exploitation and victimisation. There are several preventive measures, such as <b>organ traceability</b>, at the national and European levels, which protect donors and recipients. National authorities ensure a just and transparent organ donation and transplant programmes.</p>	<p><b>Organ trafficking is a crime</b> causing exploitation and victimisation. There are several preventive measures, such as <b>organ traceability</b>, at the national and European levels, which protect donors and recipients. National authorities ensure a just and transparent organ donation and transplant programmes.</p>
<p>Green: Relevant/important/favourable information            Red: Unclear/non-relevant information            Blue: Words/phrases with mixed perceptions            Font size: According to the frequency of the colourings</p>	

### General perception

The most important aspect of the seventh message is that it openly addresses the issue of organ trafficking. It recognises the risk and offers some additional information about the counteractive actions at the national and European levels. Although the message offers useful information and is semantically logical and clear, it evoked major fears and barriers in the discussion that might become less controllable.

The message is seen as relevant, yet it is perceived as not presenting the entire truth or, better, it leaves some questions unanswered.

### Threats to comprehensibility

Organ trafficking is clearly perceived as a worldwide social issue. Meanwhile, the decision in favour of becoming an organ donor is made in an intimate, personal space where the individual

expresses his/her position. There is a risk that these perspectives are mixed up. Therefore, messages that raise negative social issues should not be connected to the messages that support people in clarifying their personal opinion.

### Exceptions

The Hungarians and Greeks welcomed the broad control system as mentioned in the message, although some questioned its efficacy. Particularly in Hungary, it was mentioned that although organ trafficking exists it is not the fault of the national system. Organ trafficking is perceived as illegal, operating alongside the official system.

It was also noticed among decided participants from both countries that the existence of organ trafficking does not influence their decision on organ donation.

Discussion about this message revealed distrust in governmental institutions in some countries (Slovenia, Germany, Hungary – especially among undecided participants). Moreover, the message is perceived as shocking because it reminds people of sensational stories in the media.

### How to communicate

Spokespersons and communicators need to be aware that provocative questions about organ trafficking may arise. They should prepare answers with facts and correct data in order to provide reassurance. Addressing organ trafficking in the opening sentence of a communication can put the topic of organ donation in a negative context. In this case, any reference to an altruistic motivation is difficult and requires additional explanation. Preferably, messages about organ trafficking should be communicated separately.

When talking about organ trafficking, reliable data about the following should be prepared:

- the responsibilities of national authorities;
- preventive measures; and
- the allocation of donated organs.

Table 21: Strengths and weaknesses: Message 7

Strengths	Weaknesses
<ul style="list-style-type: none"> <li>• Transparency: the problem of trafficking is recognised and directly addressed</li> <li>• Additional information about the role of national authorities and preventive measures is given</li> </ul>	<ul style="list-style-type: none"> <li>• Organ trafficking brings many controversial questions into the discussion</li> <li>• The word “traceability” is not clear to some participants</li> </ul>

## 8th Message

**Cross-border organ exchange is beneficial for patients within Europe. Cross-border organ exchange enables every organ procured within Europe to be transplanted. There are several agreements on the exchange of organs donated for transplantation within Europe.**

Table 22: Colouring exercise: Message 8

Undecided groups	Decided groups
<p><b>Cross-border organ exchange is beneficial</b> for patients <b>within Europe</b>. Cross-border organ exchange enables every organ procured within Europe to be transplanted. There are <b>several agreements</b> on the exchange of organs donated for transplantation within Europe.</p>	<p><b>Cross-border organ exchange is beneficial</b> for patients <b>within Europe</b>. Cross-border organ exchange enables <b>every organ</b> procured <b>within Europe to be transplanted</b>. There are <b>several agreements</b> on the exchange of organs donated for transplantation <b>within Europe</b>.</p>
<p>Green: Relevant/important/favourable information            Red: Unclear/non-relevant information            Blue: Words/phrases with mixed perceptions            Font size: According to the frequency of the colourings</p>	

### General perception

This message stresses the value of life, independent of national borders, since it introduces the benefits of cross-border exchange. The message creates positive impressions in all groups and countries. It is a clear message, comprehensible and does not cause any controversy. It brings new and valuable information. At the same time, the message is not perceived as motivational since it does not evoke an active response. Its special content implicitly addresses organ receivers, not organ donors.

### Threats to comprehensibility

The fact that the cross-border exchange of organs exists is not clear to many people. Few have heard of it, mainly decided ones, but clear knowledge is not prevalent among the majority of participants. As a consequence, information about 'new' aspects might cause insecurities when being too general.

## Exceptions

Germans (especially undecided people) as well as Slovenians (especially decided people) felt insecure about this message. This might be explained by the general lack of trust in governmental systems and EU institutions.

## How to communicate

This message can cause conflicts between the motivation to help anyone (international altruism) and the fear of corruption since several countries are included. When communicating about cross-border exchange, the following aspects might be of interest:

- a definition of cross-border exchange;
- the transport of organs, including time limitations;
- allocation, traceability, vigilance;
- legislative aspects, e.g. an explanation of why only some countries exchange organs across borders; and
- data and statistics should be available.

It was recommended to pay attention when translating the word "beneficial" in national languages not to sound too utilitarian. The words "helpful" or "advantageous" could be used instead. In all groups, the participants suggested removing the last sentence of this message as it does not add anything relevant.

In communication, the spokesperson should anticipate possible provocative questions regarding smaller vs. bigger members of exchange networks in terms of their equality.

Table 23: Strengths and weaknesses: Message 8

Strengths	Weaknesses
<ul style="list-style-type: none"> <li>• Positive introduction to cross-border organ exchange</li> <li>• New information, more knowledge</li> <li>• Individual altruism crossing national borders</li> </ul>	<ul style="list-style-type: none"> <li>• Not very actionable and motivating</li> <li>• The general wording might raise mistrust in authorities</li> </ul>

## 9th Message

The cross-border exchange of organs leads to better results due to optimal matching between the donor and recipients and shortens the waiting time. Cross-border organ exchange enables us to better treat patients with special needs, e.g. paediatric patients, high-urgent patients.

Table 24: Colouring exercise: Message 9

Undecided groups	Decided groups
<p><b>The cross-border exchange</b> of organs leads to <b>better results due to optimal matching between the donor and the recipients and shortens the waiting time.</b> Cross-border organ exchange enables us to <b>better treat patients with special needs, e.g. paediatric and high-urgent patients.</b></p>	<p><b>The cross-border exchange</b> of organs leads <b>to better results due to optimal matching</b> between donor and recipients and <b>shortens the waiting time.</b> Cross-border organ exchange enables us <b>to better treat</b> patients with special needs, e.g. paediatric patients, in <b>high-urgent patients.</b></p>
<p>Green: Relevant/important/favourable information            Red: Unclear/non-relevant information            Blue: Words/phrases with mixed perceptions            Font size: According to the frequency of the colourings</p>	

### General perception

Messages 8 and 9 are similarly perceived as positive and comprehensible in all groups and countries. The main strength is emphasising the benefits of cross-border exchange that act as a convincing rationale: ‘optimal matching between the donor and the recipients’ and ‘shortens the waiting time’.

### Threats to comprehensibility

Mentioning special target groups like children might raise emotional burdens and provoke insecurities. Explanation of the group “patients with special needs” should be provided with care.

## Exceptions

Definitions of the term “persons with special needs” may vary from country to country. Therefore, communicators and spokespersons need to rephrase it in a semantically appropriate way.

## How to communicate

The key phrase within the message is “optimal matching” since it presents the core benefits of cross-border exchange. It would be recommended to join this benefit with the one from the 8th message (every organ can be transplanted), and it could serve as an introduction to the cross-border exchange topic.

More details should be given about the characteristics of “patients with special needs”, high-urgent patients and waiting lists.

Table 25: Strengths and weaknesses: Message 9

Strengths	Weaknesses
<ul style="list-style-type: none"> <li>• Understandable message</li> <li>• Credible statement of why cross-border exchange is important</li> <li>• Positive emotional touch point: patient (instead of recipient)</li> <li>• Positive cognitive touch points: ‘better results, optimal matching, shorter waiting times, better treatment’</li> </ul>	<ul style="list-style-type: none"> <li>• Connecting cross-border exchange with terms like “waiting times” and “children” is too complex and might trigger an emotional burden</li> </ul>

## 16 DISCUSSION

The introduction part of the focus group discussion as well as some parts of the messages’ evaluation revealed a general perception regarding organ donation and transplantation. Findings from this part of the discussions provide information on people’s understanding and their emotional drivers. Motivators, barriers and dynamics among them will be presented and the decision-making process will be explained.

### 16.1 GENERAL PERCEPTION

At first sight, organ donation seems to be a topic that requires information, facts and objective data. On the other side, the core driver of organ donation is found to be an emotional one, deriving from an intimate level – being human and daring to follow ethical principles.

It was observed in the focus group discussions that the topic of organ donation is highly emotional and characterised by opposite emotions. It gives rise to feelings connected to 'life' and 'death' (see Figure 30). Reflecting on one's own death or the death of a closely related person provokes fear and withdrawal when reflecting on or discussing it. Death is still a taboo for many people; therefore, proactively dealing with the topic of organ donation might be regarded as an emotional burden.

Reluctance regarding organ donation also occurred because of other aspects as stated by the participants:

- lack of information;
- fear of misuse in organ donation, e.g. organ trafficking, fear of harming others;
- distrust in government institutions, health organisations, doctors etc.; and
- body perception, e.g. integrity, disfigurement.

On the other hand, altruism is an idea that activates positive feelings, proudness, feelings of being a good, ethical person, showing high values, being also proud to have made a decision.

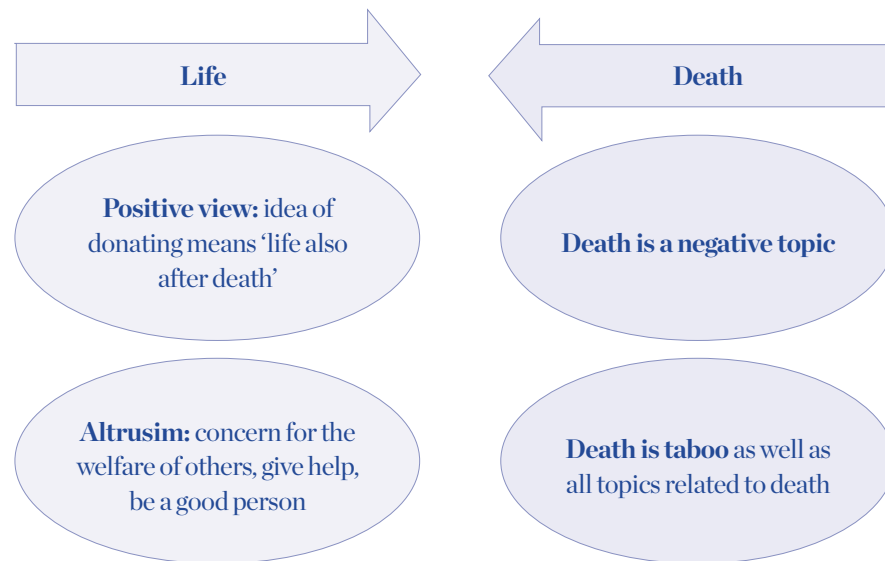


Figure 30: Emotional basis for the decision-making process

## 16.2 DYNAMICS

Making a decision about organ donation is a developmental process in which individuals need to deal with different barriers and positive drivers. Accordingly, it could be seen as a struggle between positive and negative feelings (see Figure 31).

The decision-making process mostly depends on perceived barriers and motivators and on the dynamics between them. It can be explained as an intrapersonal conversation: barriers evoke negative feelings (particularly fear) and motivators bring arguments against fear. In this process, knowledge might play the role of a 'shock absorber', as it was also frequently recognised as an important factor in studies on organ donation willingness (Horton, Horton, 1990, Morgan et al., 2002, Schulz et al., 2000).

It was noticed in all countries that decided as well as undecided participants generated mixed feelings about organ donation. However, decided participants spontaneously recalled more positive associations, demonstrated greater knowledge, a more proactive stand and dealt with the concept of death in a more detached manner. On the contrary, undecided participants were much more reluctant regarding the subject, showed a lack of information, greater scepticism and mistrust in the institutions or medical professionals.

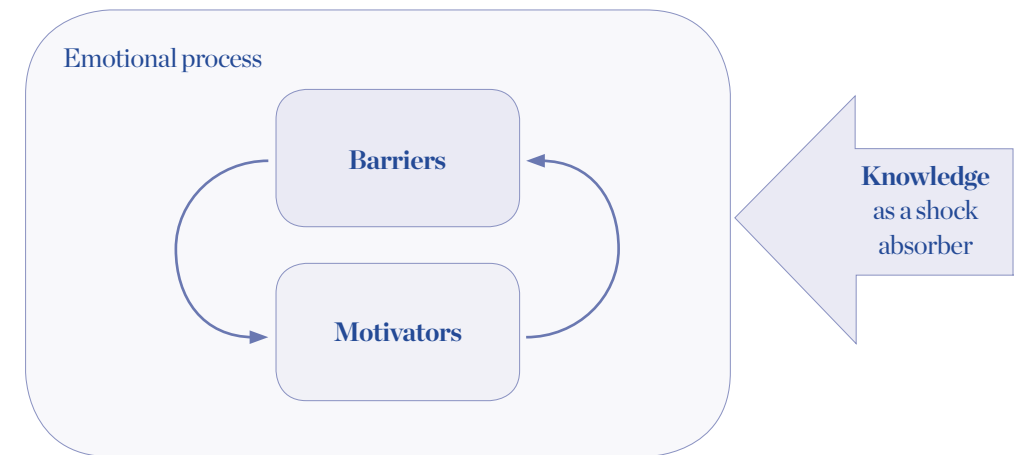


Figure 31: Framework for understanding the dynamics of barriers and motivators

Also observed in the discussions was the fact that decided participants differed from undecided ones in their past experience with organ donation. Many of the decided participants revealed a close personal experience with the issue of organ donation in the past (people close to them being either organ donors or recipients).



## 16.2.1 BARRIERS

The categorised barriers should not be seen as stages or sequences, but more as a complex process in which people deal with different barriers at the same time:

Table 26: Main barriers to organ donation

Barrier	Details
Lack of general information	<ul style="list-style-type: none"> <li>• Responsibilities and rights of a donor</li> <li>• How to declare the decision</li> <li>• Incomplete information about the procedure of organ donation</li> </ul>
Lack of medical knowledge	<ul style="list-style-type: none"> <li>• Brain death</li> <li>• Which organs might be donated</li> <li>• Cross-border exchange</li> <li>• Organ procurement</li> </ul>
Lack of trust in the system/institutions/physicians	<ul style="list-style-type: none"> <li>• Legal framework</li> <li>• Scandals, trafficking</li> <li>• Who/what supervises organ donation procedures</li> <li>• Who is responsible for the organ donation programme</li> </ul>
Personal doubts	<ul style="list-style-type: none"> <li>• Body perception</li> <li>• Fear</li> <li>• Superstitions</li> <li>• Dignity of a deceased body</li> </ul>
Social obstacles	<ul style="list-style-type: none"> <li>• Grieving process</li> <li>• Involvement and influence of others (e.g. family) in an individual's decision about organ donation</li> <li>• Culture, tradition, religion</li> </ul>

## 16.2.2 MOTIVATORS FOR ORGAN DONATION

During the discussions, the initial motivator for organ donation was identified in the idea of altruism, which is realised through contemplation about helping others, saving lives and being an ethical and socially responsible person. Decided participants stated that altruism is the main driver of their decision. For them, altruism even plays a dual role; it is the basis as well as a perpetual amplifier of their decision. Decided participants made their decision relatively quickly, without retroactively questioning it.

The second motivator to become an organ donor the participants mentioned is the concept of reciprocity. According to this concept, people may ground their decision on organ donation in two perspectives, the perspective of being an organ donor and the perspective of being a potential recipient. Reciprocity as a motivator means that people who would accept an organ should also be willing to be an organ donor.

Undecided participants also expressed positive motivations for organ donation. However, unlike the decided participants, they named many barriers when discussing their personal opinion on organ donation. Even more, these barriers were not expressed spontaneously, but later when discussing the tested messages. It became clear that the undecided participants had not paid much attention to this topic before.

## 16.3 DECISION-MAKING PROCESS

A decision to become a donor is a complex process. Three stages before making a decision on organ donation can be identified based on the focus group discussions and previously gained knowledge (Prochaska, DiClemente, 1992):

- **Sensitisation phase – emotional touch:** people develop an interest in the subject through emotional involvement. It can either be reached by personal experience or through the media presenting real-life stories of organ donors and recipients.
- **Cognitive phase:** informing, discussing and convincing. If the sensitisation phase is not followed by relevant information, the initial process stops. Similarly, if the first encounter with the subject was negative and verification of the information failed, the decision-making process is blocked, resulting in a passive stand on the topic. In the cognitive phase, people need information, facts, figures and newly gained knowledge. In this phase, people develop a perception that they are well-informed and educated, although they might not actively look for information. Many undecided participants did not reach this phase because they did not get through the first impressions presented by the media nor did they receive support to obtain relevant information and further motivating impulses.

- **Actualisation phase – decision-making:** A decision to donate an organ is mainly an emotional one, but people want to believe they have made their decision based on knowledge and information, too. In the actualisation stage, a trigger is needed, especially for undecided groups. It can be initiated by a strong, convincing, often impulsive ‘Eureka’ moment: “I can help others”. This trigger is usually a personal experience with organ donation (e.g. a close relative or friend donating or receiving an organ). If a person discloses his/her decision on organ donation in a family discussion, this might also serve as an instigator for others in actualisation of the decision-making process.

## 17 SUMMARY AND CONCLUSION

Based on the results, the following conclusions can be drawn:

- The general perception of organ donation and transplantation among the participants offered an important insight: the main motivator for the decision to become an organ donor is emotional.
- The focus group discussions revealed that organ donation and transplantation is a highly sensitive topic, which implies opposite emotions.
- Messages with a strong emotional impact are messages no. 1, 5 (the first sentence) and 9 (the first sentence). They address motivations, experiences, ideas and emotions. They focus on life (not death), benefits, personal freedom and have an optimistic character. The goals of motivational messages are to gain attention and build an emotional connection, partnership and, most importantly, trust. Motivational messages need to be short, clear and positive without superlatives.
- Objective information must also be available to the media or public because they support the decision-making process in certain phases (cognitive and actualisation phases). Objective information serves as a basis for rational decision-making. Messages with potential or actual informative power are messages nos. 3, 4, 7, 8 and 9. They deliver information, data and facts to raise the level of knowledge. The tone of communication should be straightforward and clear. The aim of such messages is to spread knowledge and raise the credibility of the communicator.
- Both types of messages – motivational and objective – are important in the communication strategy, but require different presenters (e.g. medical professionals, patients, donor families) and communication channels (e.g. the specialist media, newspapers, social media) to address potential target groups.
- People in all participating countries assess that organ donation is insufficiently presented in the media and public.
- A key motivator to become an organ donor is altruism, which is true for both decided and undecided individuals. Altruism acts as a never-ending driver of their decision, but it could be more frequently emphasised in the future.

- The most important barrier to becoming an organ donor is fear, which is frequently related to a lack of information or knowledge and mistrust in authorities.
- Decided and undecided participants generated positive and negative cognitions and emotions related to different topics in the field of organ donation and transplantation. However, decided participants spontaneously recalled more positive ideas, revealed greater knowledge, a more proactive stand and reflected upon death in a more detached manner. Undecided participants were more reluctant regarding the subject, showed a lack of information, greater scepticism and mistrust.
- Many of the decided participants revealed a personal experience with organ donation in the past.
- The decision-making process about organ donation is often long and complex as an individual processes several aspects: personal, family, institutional and ethical matters. It was confirmed in the focus group discussions that when deciding on organ donation people usually move through different phases:
  - sensitisation phase: where the main trigger is emotional;
  - cognitive phase: when facts, clear and transparent information need to be delivered; and
  - actualisation phase: when a trigger is needed to take the final decision.
- Certain situations and experiences have an important impact on the decision-making process, as mentioned by the participants. These are: experience with the need for an organ transplant or with actual organ donation in one’s family or social environment, other donation activities (blood donation), discussion with a family doctor. These situations are seen as touch points which stimulate individuals to be aware repeatedly of organ donation.

Organ donation and transplantation is a highly sensitive topic, which implies many opposite emotions (e.g. altruism and fear). An effective communication strategy implies:

- a motivational tone in order to gain attention and build an emotional connection;
- objective information to deliver information, data and facts to raise the level of knowledge;
- the characterisation of target groups, also regarding their position in the the decision-making process; and
- a continuous media coverage.

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**PART VI:**

**Crisis communication**





This chapter contains:

- a description of the role and contribution of crisis communication;
- an explanation of the mission or goals of crisis communication;
- practical examples and checklists.

## 18 GENERAL ASPECTS OF CRISIS COMMUNICATION

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Communicating in times of crisis is a special challenge and requires specific expertise and training. It involves different areas of communication: media strategy, reputation and issues management, internal communication and public affairs. Crisis communication is to be incorporated as a special topic in the general communication policy/strategy of an organisation.

This chapter describes the role and contribution of crisis communication, especially focusing on communication with the media, in managing any unforeseeable event or incident that threatens the organisation, its mission or goals. Using practical examples and checklists, this chapter aims to support professionals in organ donation and transplantation, to make them prepared for and take proper action when confronted with a crisis.

### 18.1 DEFINITION OF CRISIS

In the literature, many definitions can be found of crisis, crisis management and crisis communication. The following definitions adequately describe potential crisis situations and approaches in organ donation and transplantation:

#### **Crisis:**

A point of great difficulty or danger to an organisation possibly threatening its existence and continuity, that requires decisive change.

(Cornelissen, 2004)

A specific, unexpected and non-routine organisationally based event or series of events, which creates high levels of uncertainty and threat or perceived threat to an organisation's high priority goals.

(Seeger et al., 1998)

#### **Crisis management:**

A set of factors designed to combat crisis and to lessen the actual damages inflicted. Crisis management seeks to prevent or lessen the negative outcomes of a crisis and thereby protect the organisation and its stakeholders.

(Coombs TW, 1999)

#### **Crisis communication:**

The collection, processing and dissemination of information required to address a crisis.

(Coombs TW, Holladay SJ, 2009)

### 18.2 TYPOLOGY OF CRISES

For an organisation, it is important to have a common agreement on the categorisation of crises. It is not necessary to approach and manage every unexpected event, anomaly or mistake as a crisis. An incident can be managed in a different way than a crisis. Usually, when an event is categorised as a crisis this involves the management which needs to set up a crisis team. In a crisis, normal business processes are (temporarily) stopped to ensure the expertise and capacity of management and employees become available for crisis management.

### 18.3 THE GOALS OF CRISIS COMMUNICATION

Crisis communication is strategically important for a successful reaction to critical circumstances. The most important goal of crisis communication is to achieve that stakeholders maintain trust in the organisation and its activities. Therefore, an organisation must be able to respond promptly, accurately and confidently during an emergency or crisis. Many different audiences must be reached with information specific to their interests and needs. The image of an organisation (or even the entire 'working field') can be positively or negatively impacted by public perceptions of the way an incident is handled.

To achieve good crisis management, a coordinated crisis communication action is required. Good communication should be at the heart of a crisis management plan. Communication should reduce tension, demonstrate a commitment to correct the problem and take control of the information flow. Crisis communication involves communicating with a variety of target audiences, such as the media, the general public, employees, regulators, financiers and lawmakers.

## 18.4 GENERAL APPROACH

First of all, it is important to stress that organisations should never think “such things do not happen here”. This means that when an organisation still has to decide on the crisis communication policy and approach during a crisis, it has an additional crisis to manage. It is therefore recommended to develop a crisis communication policy during times of normal operations. Various studies have shown that organisations which were prepared for a crisis and reacted professionally were rewarded by their stakeholders and maintained trust. Organisations lost trust when they did not manage a crisis well, reacted late or provided incomplete responses to the media (e.g. “no comment”).

## 19 CRISIS COMMUNICATION IN ORGAN DONATION AND TRANSPLANTATION

The famous saying: “Losing trust takes a minute, (re)establishing trust takes years ...” is very much applicable to organ donation and transplantation. Trust is the **key** in all aspects of the process of organ donation and transplantation. When society loses trust in an organisation or the execution of an activity in this area, this has a major impact on willingness for organ donation. Multiple areas in the working field of organ donation and transplantation hold significant potential for crisis: brain death diagnosis, disease transmission, suspicion of waiting list manipulation, allocation/priority to special patients, illicit organ trafficking etc. This means that organisations which are active in the field of organ donation and transplantation not only need a solid organisation including communication activities, but also a well-established crisis management plan encompassing crisis communication. Regular exercises and trainings are advised to make sure that all staff involved in a crisis team are conscious of their role, responsibilities and what to do.

### 19.1 CURRENT EVENTS

Organ donation and transplantation requires the trust of all stakeholders involved. The general public needs to trust the ‘system’ in order to make a personal decision whether to become a donor or not. This applies to both living donation and deceased donation because both are linked in the view of the public. Patients require trust in their treating physician, transplant centre and allocation organisation (“Do I get an organ when I am eligible for it?”). The same applies to donors: “Can I be sure that I am really ‘dead’ before they take my organs out?” , “Can I be sure that my body is treated with respect?”, “Can I rely on the doctors that they make sure somebody is truly helped with my organ?”.

When trust is lacking, the natural reaction of human beings is to stay away from uncertainty which would mean no consent for organ donation.

A situation entailing the manipulation of patients’ waiting list data came to light in Germany in 2012. It showed that heavy media reporting had a very negative influence on organ donation rates. The issue was reported broadly (newspapers, radio, TV, social media) as “Organspendeskandal” (in English: organ donation scandal) (see Figure 32). The result has impacted the trust of the general public. Overall, organ donation rates dropped significantly (see Figure 33). This was also demonstrated in a study showing that even the motivation of German transplant professionals and hospital staff involved in organ donation and transplantation was negatively influenced by this ‘crisis’.



Figure 32: Media reporting on the ‘organ donation scandal’ in Germany (adopted from DSO, 2014)

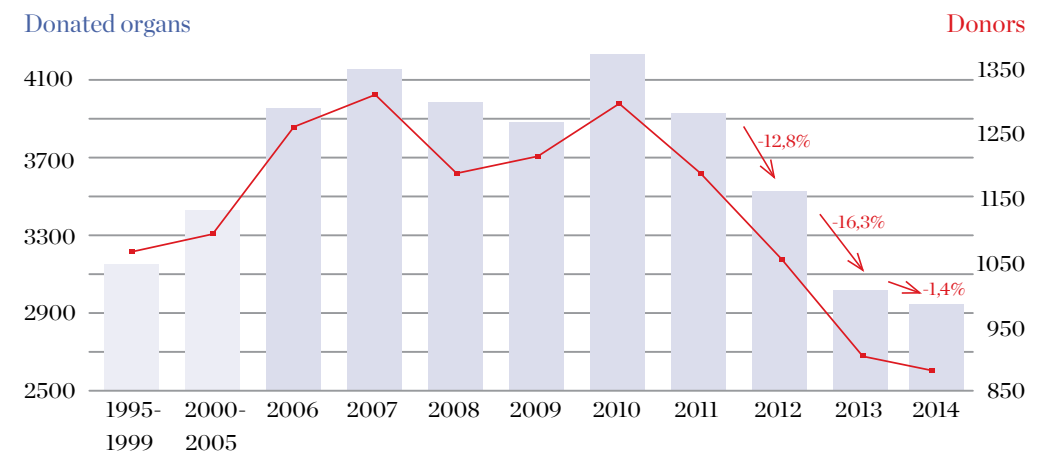


Figure 33: Organ donation in Germany (adopted from DSO, 2015)

## 19.2 POSSIBLE APPROACH

Every crisis can be different and the role of the organisation (or competent authority) also differs from country to country and from organisation to organisation. It makes a huge difference whether you are the organisation or authority which gets ‘blamed’ or if you are just affected by a crisis caused by another party in the working field.

Whatever your situation is, there are basic guidelines and steps to follow which support your approach to any ‘unforeseen’ event. The model ‘clock of mans’ is a very practical tool to support the crisis communication approach (see Figure 34). The model was developed by the Dutch consulting company KappetijnBriks Advies.

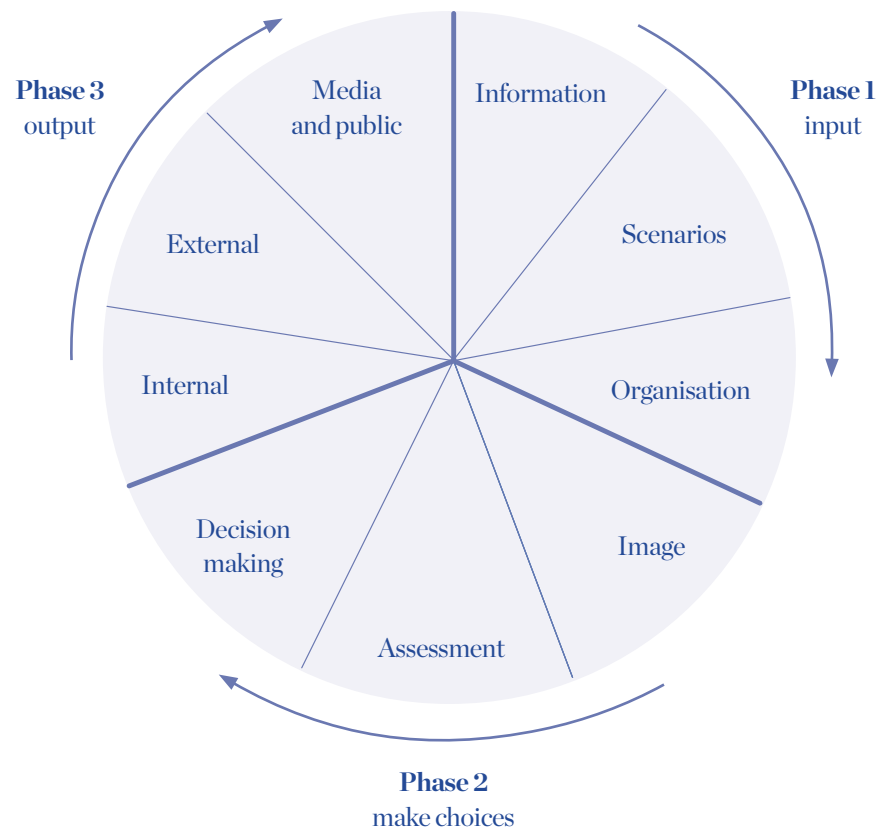


Figure 34: The ‘Clock of Mans’ model (adopted from KappetijnBriks Advies, 2015)

### Phase 1: Information, scenarios, organisation

- Draw the landscape: what is happening here?
- Define the position: what is our role/responsibility in this situation?
- Appoint a team of specialists (e.g. experts, spokesperson)

### Phase 2: Image, assessment, decision-making

- Fully agree about the situation and expectations (scenarios)
- Decide on the communication strategy: proactive/reactive and key principles

### Phase 3: Communicate with stakeholders, the media, the public

- Make use of various communication tools: web, social, email, phone
- Act according to key communication principles
- Continuous media monitoring: (tweetdeck) – what is said/written about this topic
- Make a time schedule for your communication moments: be aware of the principle “informed waiting reduces stress”

## 19.3 GUIDELINES AND RECOMMENDATIONS

As a basic guideline for crisis communication, the following recommendations can be used:

- Always act and stick to the core values of the organisation
- Communication based on facts (no speculation)
- Invest in a good network
- Create a team: internal, external etc. (close cooperation with partners)
- Create a structure
- Always keep your employees informed!

During phase 3 – execution of crisis communication – the following guidelines apply:

- Accuracy before speed
- High level of availability for the media – Informed waiting reduces stress
- Support journalists to bring them into contact with the ‘right’ persons
- Keep control: the timing of your press releases
- Constantly check the phases: new information, new decisions?
- Cooperate with other parties (authorities)
- Always keep your employees informed!

## 20 EXPERIENCE FROM A CASE STUDY

The practical applicability of the guidelines and recommendations mentioned above was confirmed by practitioners: In a workshop held in Ljubljana in July 2014, various ‘crisis’ scenarios in the field of organ donation and transplantation were discussed by representatives of European NCAs. The cases used had really happened in the past.

### ‘Crisis scenario’ – example

A 17-year-old girl receives a heart and lung transplant. At the end of the surgery, it was found that the blood group was wrong (organs of blood group A, recipient blood group O). The patient was in a serious condition. (Duke Medicine, 2003)

#### • What would you – as a PR expert – recommend that the hospital do?

The family of the transplanted patient informs the media. The girl was re-transplanted 13 days later. The girl died two days after the 2nd surgery.

#### • What would you – as a PR expert – recommend that the hospital management do?

In small working groups, a crisis communication approach for this scenario was developed. Based on the results, the following approach for media communication was recommended:

- Call the crisis team together in a meeting: go through all the facts, responsibilities, measures (broad representation specialists: medical director, PR expert, legal adviser etc.)
- Choose a spokesperson to communicate with the media (director, surgeon, PR expert): the person in charge has to be confident and have good communication skills (be aware of non-verbal communication!)
- Prepare a press conference (aim: to show care and demonstrate measures. Deal with all issues at once)
  - Select who to invite for a press conference (media mix, radio, TV, newspapers, science magazines etc.) and inform affected persons beforehand (in the scenario this would concern the family of the patient, hospital staff)
  - Define your key messages, prepare statements, Q&As
  - Take responsibility if you are responsible, address apologies to affected persons (if applicable)
  - Explain measures taken and measures that prevent reoccurrence
  - Present events in chronological order, a detailed explanation, honest and checked information

- Install and continuously update your newsroom, media monitoring (discussions and react)
- Take care of communication towards other stakeholder groups, with special attention to:
  - patients on the waiting list
  - patients currently under treatment in a hospital
  - authorities
  - share experience (e.g. other transplant centres)

## 21 SUMMARY

The most important goal of crisis communication is to ensure that stakeholders **maintain trust** in the organisation and its activities. Therefore, an organisation must be able to respond promptly, accurately and confidently during an emergency or crisis.

Trust is the key in all aspects of the organ donation and transplantation process. When society loses trust in an organisation or the execution of an activity in this area, this has a major impact on willingness for organ donation. This means that organisations active in the field of organ donation and transplantation need a well-established crisis management plan including crisis communication. Regular exercises and trainings are advised to make sure all staff involved in a crisis team are conscious of their role, responsibilities and what to do.

The focus in this chapter is on communication with the press because the media has a big impact on public debate and opinion-making in society. This chapter provides a practical checklist, basic guidelines and steps to follow in support of an organisation when communicating regarding any ‘unforeseen’ event, with a particular focus on crisis communication.



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## APPENDIX I – FOEDUS CONSORTIUM

### PROJECT COMMITTEE

1. Istituto Superiore di Sanità / Centro Nazionale Trapianti \* National Institute of Health / Italian National Transplant Centre (ISS-CNT) – Italy
2. Országos Vérellátó Szolgálat \* Hungarian National Blood and Transfusion Service (OVSZ) – Hungary
3. Εθνικός Οργανισμός Μεταμοσχεύσεων \* Hellenic Transplant Organisation (EOM) – Greece
4. Stichting Eurotransplant International \* Eurotransplant International Foundation (ETI) – The Netherlands
5. Agence de la biomédecine (ABM) – France
6. Koordinační Středisko Transplantací \* Czech Transplantation Coordinating Centre (KST) – Czech Republic
7. Zavod Republike Slovenije za Presaditve Organov in Tkiv \* Institute for Transplantation of Organs and Tissues of the Republic of Slovenia (ST) – Slovenia
8. Deutsche Stiftung Organtransplantation \* German Organ Transplantation Foundation (DSO) – Germany
9. Federal public service Ministry of Health Belgium (FPS PH) – Belgium
10. Ministarstvo Zdravlja Republika Hrvatska \* Ministry of Health of the Republic of Croatia (MOH RC) – Croatia
11. Изпълнителна агенция по трансплантация \* Bulgarian Executive Agency for Transplantation (BEAT) – Bulgaria
12. Nacionalinis Transplantacijos Biuras \* National Transplant Bureau under the Ministry of Health of the Republic of Lithuania (NTB) – Lithuania
13. Ministry for Health, the Elderly and Community Care (MHEC) – Malta
14. Instituto Português do Sangue e da Transplantação, IP (IPST) – Portugal
15. Narodna Transplantačná Organizácia \* National Transplant Organisation (NTO) – Slovakia
16. NHS Blood and Transplant (NHSBT) – The United Kingdom
17. Centrum Organizacyjno-Koordynacyjne Do Spraw Transplantacji \* Polish Transplant Coordinating Centre (POLTRANSPLANT) – Poland
18. Institutul Clinic Fundeni \* Fundeni Clinical Institute (FCI) – Romania

### ADVISORY BOARD

1. Igor Codreanu – Renal Foundation Moldova – Moldova
2. Bernadette Haase – Dutch Transplant Foundation – The Netherlands
3. Jórlaug Heimisdóttir – Directorate of Health – Iceland
4. Pål Foyen Jørgensen – Oslo University Hospital, Rikshospitalet – Norway
5. Tanel Laisaar – Ministry of Social Affairs – Estonia
6. Rafael Matesanz – National Transplant Organization – Spain
7. Franziska Beyeler – Swisstransplant – Switzerland (external member)

## APPENDIX II – FINDINGS OF THE LITERATURE ANALYSIS

	Reference	Theory-based publications	Practice-oriented publications	Excluded from further analysis due to limited relevance
1.	Al-Khader AA, Shaheen F (1999) <b>Strategies for increasing transplantation: the Saudi experience.</b> In: Transplantation Proceedings, 31, p. 3278.			x
2.	Cameron AM, Massie AB, Alexander CE, Stewart B, Montgomery RA, Benavides NR, Fleming GD, Segev DL (2013) <b>Social media and organ donation registration: The Facebook effect.</b> In: American Journal of Transplantation, 13, pp. 2059–2065.		x	
3.	Cantarovich M, Birk P, Ekbeq H, Delmonico F, Schoenberg R, Garcia C, Manyalich M, Wall W, Arbogast H, Sherry W, Young-Kipp S, Cantarovich F (2013) <b>First global forum on education on organ donation and transplantation for schools.</b> In: Pediatric Transplantation, 17, pp. 12–18.			x
4.	Conesa C, Ríos A, Ramírez P, Rodríguez MM, Rivas P, Canteras M, Parrilla P (2003) <b>Psychosocial profile in favor of organ donation.</b> In: Transplantation Proceedings, 35, pp. 1276–1281.	x		
5.	Cossé TJ, Weisenberger TM (2000) <b>Words versus actions about organ donation: A four-year tracking study of attitudes and self-reported behaviour.</b> In: Journal of Business Research, 50, pp. 297–303.		x	
6.	Feeley TH, Moon SI (2009) <b>A meta-analytic review of communication campaigns to promote organ donation.</b> In: Communication Reports, 22/2, pp. 63–73.		x	
7.	Gäbel H, Rehnqvist N (1997) <b>Information on new transplantation legislation: How it was received by the general public and the action that ensued.</b> In: Transplantation Proceedings, 29, p. 3093.		x	

	Reference	Theory-based publications	Practice-oriented publications	Excluded from further analysis due to limited relevance
8.	Garcia VD, Goldani JC, Neumann J (1997) <b>Mass media and organ donation.</b> In: Transplantation Proceedings, 29, pp. 1618–1621.		x	
9.	Gassmann C, Vorderer P, Wirth W (2003) <b>Ein Herz für die Schwarzwaldklinik? Zur Persuasionswirkung fiktionaler Fernsehunterhaltung am Beispiel der Organspende-Bereitschaft (the persuasiveness of fictional television entertainment using the example of organ donation willingness).</b> In: Medien und Kommunikationswissenschaft, 51/3–4, pp. 478–496.			x
10.	Gold SM, Schulz KH, Koch U im Auftrag der Bundeszentrale für gesundheitliche Aufklärung (BZgA) (2001): <b>Der Organspendeprozess: Ursachen des Organmangels und mögliche Lösungsansätze: Inhaltliche und methodenkritische Analyse vorliegender Studien - Eine Expertise (The organ donation process: causes of the organ shortage and possible solutions).</b> Köln: BZgA.			x
11.	Hart LaVail K, Anker AE, Reinhart A, Feeley TH (2010) <b>The persuasive effects of audiovisual PSAs to promote organ donation: The mediating role of psychological reactance.</b> In: Communication Studies, 61/1, pp. 46–69.	x		
12.	Heuer M, Remmer N, Radünz S, Frühauf N, Canbay A, Paul A, Kaiser G (2011) <b>Organspendebereitschaft: Interventionsstudie bei 974 Befragten (organ donation willingness - interventional study involving 974 respondents).</b> In: Zentralblatt für Chirurgie (manuscript submitted).			x
13.	Horton RL, Horton PJ (1990) <b>Knowledge regarding organ donation: Identifying and overcoming barriers to organ donation.</b> In: Social Science and Medicine, 31/7, pp. 791–800.	x		

14.	Jones SC, Reis S, Andrews KL (2008) <b>Communication about organ donation intentions: Formative research for a social marketing program targeting families.</b> Partnerships, Proof and Practice – International Nonprofit and Social Marketing Conference 2008 – Proceedings.			x
15.	King AJ, Williams EA, Harrison TR, Morgan SE, Havermahl T (2012) <b>The “Tell Us Now” campaign for organ donation: Using message immediacy to increase donor registration rates.</b> In: Journal of Applied Communication Research, 40/3, pp. 229–246.			x
16.	Kopfman JE, Smith SW, Ah Yun JK, Hodges A (1998) <b>Affective and cognitive reactions to narrative versus statistical evidence organ donation messages.</b> In: Journal of Applied Communication Research, 26/3, pp. 279–300.	x		
17.	Krekula LG, Malenicka S, Linder M, Tibell A (2009) <b>From words to action – Influence of two organ donation campaigns on knowledge and formal decision making.</b> In: Clinical Transplantation, 23, pp. 343–350			x
18.	Logar Zakrajšek B, Avsec D (2011) <b>Report on awareness rising potential of the EDD guidelines (research survey).</b> Accessible at: <a href="http://www.europeandonationday.org">www.europeandonationday.org</a>			x
19.	Lwin MO, Williams JD, Lan LL (2002) <b>Social marketing initiatives: National Kidney Foundation’s organ donation programs in Singapore.</b> In: Journal of Public Policy and Marketing, 21/1, pp. 66–77.			x
20.	Manyalich M, Paredes D, Ballesté C, Menjívar A (2010) <b>The PIERDUB project: International project on education and research in donation at University of Barcelona: Training university students about donation and transplantation.</b> In: Transplantation Proceedings, 42, pp. 117–120.			x
21.	Matesanz R (2002) <b>Organ donation, transplantation, and mass media.</b> In: Transplantation Proceedings, 35, pp. 987–989.			x
22.	Matesanz R, Miranda B (1996) <b>Organ donation – the role of the media and of public opinion.</b> In: Nephrology Dialysis Transplantation, Editorial Comment, pp. 2127–2128.			x

	Reference	Theory-based publications	Practice-oriented publications	Excluded from further analysis due to limited relevance
23.	Morgan SE, Miller J (2001) <b>Beyond the organ donor card: The effect of knowledge, attitudes, and values on willingness to communicate about organ donation to family members.</b> In: Health Communication, 14(1), pp. 121–134.			x
24.	Morgan SE, Miller J, Arasaratnam L (2002) <b>Signing cards, saving lives: An evaluation of the worksite organ donation promotion project.</b> In: Communication Monographs, 69/3, pp. 253–273.	x		
25.	Morgan SE (2009) <b>The intersection of conversation, cognitions, and campaigns: The social representation of organ donation.</b> In: Communication Theory, 19, pp. 29–48.			x
26.	Morgan SE, Harrison TR (2010) <b>The impact of health communication research on organ donation outcomes in the United States.</b> In: Health Communication, 25, pp. 589–592.			x
27.	Paez G, Valero R, Manyalich M (2009) <b>Training of health care students and professionals: A pivotal element in the process of optimal organ donation awareness and professionalization.</b> In: Transplantation Proceedings, 41, pp. 2025–2029.			x
28.	Persijn GG, van Netten AR (1997) <b>Public education and organ donation.</b> In: Transplantation Proceedings, 29, pp. 1614–1617.		x	
29.	Quick BL, Bosch D, Morgan SE (2012) <b>Message framing and medium considerations for recruiting newly eligible teen organ donor registrants.</b> In: American Journal of Transplantation, 12, pp. 1593–1597.			x
30.	Rady MY, McGregor JL, Verheijde JL (2012) <b>Mass media campaigns and organ donation: Managing conflicting messages and interests.</b> In: Medical Health Communication and Philosophy, 15, pp. 229–241.			x

31.	Reinhart AM, Marshall, HM, Feeley TH, Tutzauer F (2007) <b>The persuasive effects of message framing in organ donation: The mediating role of psychological reactance.</b> In: Communication Monographs, 74/2, pp. 229–255.	x		
32.	Sanner MA, Hedman H, Tufveson G (1995) <b>Evaluation of an organ-donor campaign in Sweden.</b> In: Clinical Transplantation, 9, pp. 326–333.		x	
33.	Schulz K H, Meier D, Clausen C, Kuhlencordt R, Rogiers X (2000) <b>Predictors of the intention to donate organs: An empirical model.</b> In: Transplantation Proceedings, 32, pp. 64–65.	x		
34.	Siminoff LA, Burant CJ, Ibrahim SA (2006) <b>Racial disparities in preferences and perceptions regarding organ donation.</b> In: Journal of General Internal Medicine, 21, pp. 995–1000.			x
35.	Weber K, Martin MM, Corrigan M (2006) <b>Creating persuasive messages advocating organ donation.</b> In: Communication Quarterly, 54/1, pp. 67–87.	x		
36.	Wolf JS, Servino EM, Nathan HN (1997) <b>National strategy to develop public acceptance of organ and tissue donation.</b> In: Transplantation Proceedings, 29, pp.1477–1478.			x
37.	Yoo JH, Tian Y (2011) <b>Effects of entertainment (mis) education: Exposure to entertainment television programs and organ donation intention.</b> In: Health Communication, 26, pp. 147–158.	x		



## APPENDIX III – QUESTIONNAIRE SURVEY

### Dear FOEDUS partner,

In work package 7 we would like to determine best communication strategies about organ donation and cross-border organ exchange in order to support your efforts when trying to raise public awareness on this topic. As we would also like to meet your needs in public relations, we kindly ask you to answer the questions below.

Please send information in English. At the questions with multiple-choice, please mark your chosen answer with a different colour of font. Thank you for your cooperation.

1. Country: \_\_\_\_\_

2. Your name: \_\_\_\_\_

### PART 1: MEDIA EXPERIENCE

3. How many times per year are you (or the person in charge for contacts with media) contacted (invited) from media to talk about organ donation and transplantation?

- a) 0-3 times
- b) 4-6 times
- c) 7-10 times
- d) 10-15 times
- e) More than 15 times; please write approximate number: \_\_\_\_\_

4. When preparing material for media (press conferences, interviews...), do you get help from a public relations expert?

- a) Yes  
*If yes: what kind of help do you ask for/receive (please describe shortly):*
- b) No

5. Did you (or the person in charge for contacts with media) get any training (workshop) in public relations (like rhetoric, how to organise press conference, how to answer difficult questions...) in the past? If yes, what kind of?

- a) Yes  
*If yes: what kind of training did you take (please describe shortly):*
- b) No

6. In the past, did you find any books, articles, guidelines or lectures on communication with media about organ donation that you find useful?

- a) Yes  
*If yes: could you please write down the reference:*

b) No

7. Which topic about organ donation is the media in your country usually interested to? (*more than one answer is possible*)

- a) General aspects of organ donation (who can become an organ donor, who are possible recipients, who gets the organs, ...)
- b) Professional issues on organ donation (diagnostics of death, surgery techniques, coordination of organ transplantation...)
- c) Possibilities of declaration for organ donation
- d) Personal life stories of transplant recipients/organ donor families
- e) Legislation issues of organ donation and transplantation
- f) Other, what: \_\_\_\_\_

8. Which topic regarding organ donation/transplantation do you find most difficult to explain in media? (*more than one answer is possible*)

- a) General aspects of organ donation (who can become an organ donor, who are possible recipients, who gets the organs, ...)
- b) Professional issues on organ donation (diagnostics of death, surgery techniques, coordination of organ transplantation...)
- c) Possibilities of declaration for organ donation
- d) Personal life stories of transplant recipients/organ donor families
- e) Legislation issues of organ donation and transplantation
- f) Other, what: \_\_\_\_\_

9. Which media do you find most difficult to give information on organ donation/transplantation to?

- a) Interviews for daily newspapers or magazines
- b) Interviews for TV shows
- c) Interviews for radio
- d) Writing for web pages
- e) Answering internet forums
- f) Other; which: \_\_\_\_\_

10. Was there any 'hot topics' regarding organ donation and transplantation in your country in the last years?  
a) Yes  
*If yes, please describe shortly:*

b) No

**PART 2: MEDIA INFLUENCE**

11. Are there any events published in the media in your country that in your opinion influenced the donation rates positively; e.g. supporting organ donation or transplantation by celebrities, presentations or stories told by patients or donor families, etc.?  
*Please describe shortly; List the most important references:*

12. Why do you think this event/these events had a positive effect on the donation rate?  
*(explain shortly)*

13. Are there any events published in the media in your country that in your opinion influenced the donation rates negatively; e.g. wrong brain death diagnosis, allocation problems, cross-border exchange problems, other scandals regarding transplantation or donation?  
*Please describe shortly; List the most important references:*

14. Why do you think this event/these events had a negative effect on the donation rate?  
*(explain shortly)*

15. Are there any campaigns, commercials, or other advertising activities supported or financed by official institutions or other bodies (Ministry of Health, OPO, competent authority, etc.) regarding organ donation and/or transplantation?  
*Please describe shortly; List the most important references*

16. Did/do they have an effect on the organ donation rate? Please explain shortly

17. Are there any measurements/results available?

18. What are your expectations or needs of this work package?  
(Which topics should be covered?)

## APPENDIX IV – INDIVIDUAL EVALUATION PROTOCOL

*Example: Message 1*

Message 1: Everyone can declare his willingness on organ donation.				
1. Please use green and red colour to underline any specific words or phrases that stand out in the message. Green: very important information Red: not understandable, not clear information – needs more explanation				
2. Individual Questionnaire Thinking about this message, to what extent do you agree or disagree with the following statements:				
	Strongly agree	Somewhat agree	Somewhat disagree	Strongly disagree
I have a generally favourable overall reaction to the message	1	2	3	4
The message is likely to catch my attention	1	2	3	4
The message is relevant to me	1	2	3	4
The message is clear	1	2	3	4
The message includes all the important information about organ donation	1	2	3	4
The message told me something new (I did not know that)	1	2	3	4



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