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## Special article

# International Collaborative Donor Project<sup>☆</sup>



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## ABSTRACT

The International Donor Collaborative Project (PCID) research group was created in 1996 in Spain with the aim of promoting research in the field of organ donation and transplantation, led by Spanish surgeons. During this period they have developed the questionnaires of the PCID, both the attitude towards cadaver and live donation, which are the most used questionnaires in publications in indexed journals. They have been the driving group of stratified studies representative of the populations under study, and of the performance of multivariate statistical analyses in the field of psycho-social research in organ donation and transplantation. The main contributions of the group focus on the analysis of health center professionals and emerging migrant groups. In recent years, studies have been extended to the United States, Latin America (mainly Mexico) and Europe.

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## Proyecto colaborativo internacional donante

## RESUMEN

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El grupo de investigación Proyecto Colaborativo Internacional Donante (PCID) surge en el año 1996 en España con el objetivo de potenciar la investigación en el campo de la donación y el trasplante de órganos, liderado por cirujanos españoles. Durante este período han desarrollado los cuestionarios del PCID, tanto el de actitud hacia la donación de cadáver como de vivo, que son los cuestionarios más utilizados en publicaciones en revistas indexadas. Ha sido el grupo impulsor de estudios estratificados representativos de las poblaciones a estudio y de la realización de análisis estadísticos multivariantes en el campo de las investigaciones psicosociales en la donación y el trasplante de órganos. Las principales aportaciones del grupo se centran en el análisis de los profesionales de centros sanitarios y en grupos emigrantes emergentes. En los últimos años, se han extendido los estudios a Estados Unidos, Latinoamérica (principalmente México) y Europa.

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Organ transplantation has been one of the most spectacular advances made in medicine. It is an example of how modern medicine has progressed extraordinarily thanks to its traits of teamwork, superspecialization and its multi- and interdisciplinary nature. The combination of numerous factors, including the development of various branches of medical and basic sciences as well as technologies, have made transplantations, which were still a distant challenge in the middle of the 20th century, a routine procedure of medical practice today.

The role of surgeons is fundamental to the advancement of transplantation programs, and their work should not be limited only to the surgical part. Surgeons should enhance the overall effects, since, given its peculiarities, transplantation is a therapy that cannot be performed at any time as it requires organ donation. It is a special therapy, with no fixed schedule in most cases that requires special dedication in time and effort.

In this context, essential aspects to increase organ donation rates should be very clear. The first is to have an infrastructure that allows donation to be conducted in all healthcare regions of the country. To this end, Spain has a model developed by the National Transplant Organization (NTO) that has made our country the world leader in donation rates, surpassing the barrier of 40 donors per million inhabitants. This system is known worldwide as the "Spanish model" and is an international point of reference when talking about promoting organ donation.<sup>1</sup> In this model, the hospital transplant coordinator is the cornerstone of the program.

The second aspect is the optimization of donation by promoting multiple-organ donation, donation after cardiac death, living donation and special techniques (split and domino transplantation in liver transplantation, cross-transplantation, etc.). In Spain, these 2 aspects are highly developed and the work of the NTO has been key in this regard.<sup>1</sup>

The third aspect is to reduce refusal to donate rates, which continues to be a key factor of donation rates. Thus, between the years 2012 and 2016, 1690 donations were lost due to refusals, representing a loss of 4100 organs that could potentially have been transplanted.<sup>2</sup> For this purpose, two factors are important. The first is transplant coordination team training, for which the Spanish NTO has developed specific courses<sup>2</sup> that have been shown to be highly effective. The second is to determine the social reality that surrounds us and to detect groups who are unaware of the significance of donation and require a special approach to obtain organ donation. Hence the importance of psychosocial studies before donation to detect these groups in anticipation, intending to continue improving donation rates. This activity should not be left alone in the hands of transplantation coordinators; the involvement of the rest of the members of the transplant team, including surgeons, is fundamental and will be important in its future progress.

Given this situation, a research group led by surgeons emerged in 1996 with the aim to promote research in the field of organ donation and transplantation, called the Donor Project. The ultimate goal was to increase donation rates by decreasing family refusal rates in cadaver donation and

promoting live donation. The first step was the development of validated tools (opinion-attitude questionnaires), which would allow us to determine these parameters with certain reliability given the non-existence of validated questionnaires and the great heterogeneity of existing ones. In those years, the questionnaires of the International Donor Collaborative Project (PCID) were designed, for both cadaver and live donations, which have been cited in more than 300 publications in indexed journals. In addition, there is a need to provide quality psychosocial studies, with stratification of the samples as well as complete bivariate and multivariate statistical analyses to be representative of the populations studied, because there have been many inadequate and biased psychosocial studies of low methodological quality.

The work chronology of the group has evolved with the needs of the coordinating teams, the appearance of new social groups and the findings of the different studies conducted.

After the initial formative studies in adolescents,<sup>3,4</sup> the first projects in the general population were done to determine the social groups that are least likely to donate with the intention of creating targeted campaigns to improve their attitude. A population study (n=2000), stratified by age, sex and geographic location, observed that 63% of the population is in favor of donation. The population profile identified as unfavorable towards organ donation is "A person over 50 years of age with primary or lower education, who does not take part in nor wants to take part in prosocial activities, who has fears about cadaver manipulation and who does not understand the concept of brain death." These early studies already show the effectiveness of transplant coordination in obtaining negative rates lower than the percentage of population not in favor of donation.

One of the most interesting aspects derived from this project<sup>5</sup> was to analyze the important impact that health center professionals have on the attitude of the population towards donation. As shown in Fig. 1, among the population that had received information about donation by medical professionals, 89% were in favor of donating their organs compared to 65% of those who had not. In addition, it was observed that if the information transmitted by the professionals was positive, 93% were in favor; however, if this was not favorable, only 44% were in favor, and it was more difficult to later reverse the negative opinions based on information provided by healthcare professionals.<sup>6-8</sup>

This fact influenced subsequent lines of research, which focused on hospital physicians, since it would be more effective to assess the situation in this opinion-generating group and their awareness than in any population campaign. The studies showed some data that, although they could be suspected, were surprising. In a sample (n=1262) stratified by work category and department type in Spanish hospitals with transplantation units, only 69% of the respondents were in favor of donating their organs after death,<sup>9</sup> which is similar to the rate reported in the general population. Moreover, when focusing on the departments related with transplantation (generating units, transplantation units and follow-up units), which at least theoretically must be more informed, a study stratified by department and occupational category (n=309)

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