

Press release

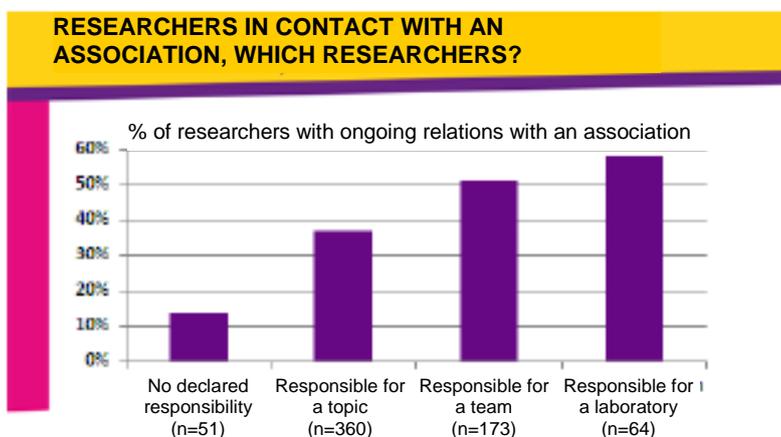
First results of survey into relations between Inserm researchers and patient associations

Results to be unveiled during the 6th Inserm meeting with patient associations held at the French Senate

In conjunction with the Senate Commission for Social Affairs, Inserm has organised the 6th meeting between national research representatives and patient associations, to be held on Thursday, 31 January 2013. More than twenty researchers and association representatives will provide first-hand accounts and develop dialogue with the senators in front of more than 250 participants. During this event, the results of a large survey conducted on some 600 researchers from Inserm laboratories will be published to shed light on relations with patient associations. According to the results, 81% of researchers surveyed are in contact with patient associations, half of which are regular contacts. More than 400 different associations were cited by name. Two thirds of researchers in contact with an association consider the fact that "direct contact with patients provides additional motivation to research activities" to be "useful" or "determining".

This year, the 6th National Research and Patient Association meeting aims to review and prepare the future prospects for a process that is gathering momentum: not only do relations between the world of research and patient associations exist, they are expanding and are actually involved in research progress, and, as a consequence progress in terms of the health of our fellow citizens. From now on these meetings will be used as a driving force for innovation and transformation in terms of relations between research and society at large.

The survey was a Gram₁ initiative (think-tank with patient associations) and was conducted on Inserm researchers in 2012 to improve knowledge and understanding of the type of relations (and their mechanics) that researchers forge with associations and how they perceive this partnership. The first results will be presented during this meeting.



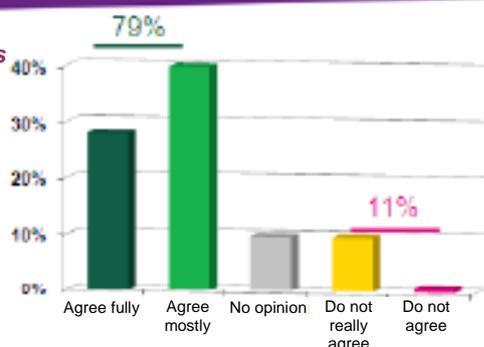
Six hundred and fifty researchers took part in this survey. 81% of them had contact with associations, half of which were ongoing. When asked to cite the name of the associations, more than 400 associations were cited by name (in addition to major associations with which everyone is familiar). Researchers who are also clinical practitioners are twice as likely to have relations with associations as their non-clinical colleagues.

The results show that researchers build up these relations over time. Relations increase in line with the researchers' age and level of responsibility: 11% of researchers aged under 30 have ongoing relations with associations, 57% of researchers aged between 50-55 and 50% of 55-60 year olds. In less than half of all cases, the researchers stated they received financial support. The amount over the total length of collaboration is extremely variable: lower than €40,000 in one out of four cases; and

greater than €2,500,000 in 5% of cases. The researchers underlined the possibilities opened up by this support: seed-funding for projects and sponsorship of doctorates or post-doctorates. For their part, researchers support the associations in the field of scientific information for patients, outreach activities, participation in meetings and scientific monitoring. Researchers recognize the important role of scientific mediator, undertaken by associations for patients, meaning four out of five researchers agree with the following statement: *"Patient associations are best placed to distribute information to the patients they represent"*.

THE OPINION OF RESEARCHERS WITH REGARD TO ASSOCIATIONS

"Patient associations are best placed to distribute information to the patients they represent"



When questioned on benefits in terms of progress in their research, half the researchers consider that information provided by the associations concerning the patients' daily life and their expectations helps them in their research. Beyond the support, financial or otherwise, provided for their projects, two thirds of researchers consider that working with a patient association provides a useful, or even determining, motivation for their activity, and 80% of them consider it enhances the value of research results.

In response to the statement: "Being involved in patient associations risks impeding researchers' scientific freedom", 70% of the researchers said they did not agree, and this figure rose to 77% for those with ongoing relations with an association. When asked whether "involvement with a patient association hinders their activity by taking up too much of their time", more than half the researchers disagreed (this figure again rose to nearly two thirds for researchers with ongoing relations with an association).

The first results of Cairnet demonstrate that patient associations are present in the world of researchers, which goes against the image of researchers 'cut-off' in their laboratories.

The vast majority of researchers surveyed now consider patient associations not only as contacts but also as players who encourage their research activities. Clarification provided by the researchers themselves must make it possible to ensure even greater progress in these partnerships, which are supported by Gram at Inserm.

For further information:

¹ Inserm was supported by the Patient Association Think-tank (Gram) to organize this meeting. Chaired by Pr Syrota, Inserm CEO, Gram is composed of 20 members, half of which are representatives from patient associations, disabled persons or family members, and the other half is made up of Inserm researchers and managers. "It is a unique location for open exchanges and debates into all issues that link research activities, the resulting progress in knowledge and the persons likely to benefit" states Martine Bungener, Gram Chairwoman.

Sources

[Key figures from the Cairnet survey](#)

[The minutes of the Senate meeting](#)

Contacts

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