



## PANDÉMIES, ÉTHIQUE, SOCIÉTÉ



***NGOs: essential for cohesion in society but almost perfectly ignorant about the role they could play***

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Within the platform of the Espace Éthique dedicated by AP-HP to pandemic preparedness, a workgroup was in charge of the question of volunteers and NGOs potential involvement.

Many non public organizations working in the field of disabilities and patients associations have been contacted. But we noticed that pandemic preparedness was not truly a priority for NGOs. 1,100 000 associations and NGOs are officially registered in France, for approximately 14 million volunteers.

Our workgroup conducted a survey in order to assess how the pandemic risk is perceived in French associations. NGOs awareness was worth to be tested as they play a key role to keep social cohesion. For example, patients associations are greatly helpful to a lot of ill people as they support them in their everyday life.

### **The pandemic flu: so familiar and so far**

What does the pandemic risk mean for NGOs? To answer this question, we interviewed about 30 associative networks representatives. Moreover, we sent a questionnaire to 1 400 non-profit organizations and collected 926 responses. We noticed that those who usually work to prevent health or social crisis were particularly prone to respond. We tried to collect responses from a wide range of association representatives (from the national level to the local one), especially those who work in the areas of health and health related humanitarian causes.

Are NGOs aware of the pandemic risk? What information do they have and share? The results brought by our survey are quite worrying. A third of the population of NGOs just ignores the risk as they consider it has nothing to do with the sense of their involvement in society.

Local volunteers lack information about the pandemic risk<sup>1</sup> and are perfectly aware of that. Pandemic flu has been a hot topic in the media for months and has since vanished from headlines. Then a curious feeling is brought forward by the survey: interviewed representatives seem to sway between a “knowing too much” and a “not knowing enough” impressions. Pandemic flu is not sensational news any more. The general impression is that we should not worry about it.

The associative networks that are the most aware of the pandemic risk are dedicated to healthcare and humanitarian causes. Nevertheless, only a few of them have launched a specific work on flu pandemic. Only about ten of major NGOs have spread information within their networks about such a threat. Volunteers working in the field almost never benefit from it. Therefore, we can not rule out a risk of panic among the French NGOs if a severe pandemic occurred. It must be emphasized that only a small proportion of non-profit organizations are familiar with health related issues.

### **Which preparedness do we want in society?**

We need to dissociate the discourse about flu pandemic from passion and anguish connotations. Volunteers will need clear rules and procedures if we want to avoid a wide disruption in NGOs. For them who are accustomed to help ill and disabled people, it could lead to a major worsening of vulnerable conditions. In other words, a panic among non-profit organisations will aggravate vulnerabilities.

At this point, we can separate two sorts of associations: those who are daily involved in care and those whose vocation stands far from care. In a pandemic state, the second category would be mobilized only if the crises had to be very severe.

The willingness to intervene in a pandemic time is very difficult to point up. Half of the associations which answered explained that “they would possibly intervene”. We are far from a sharp commitment. We are not doing what would sway non-profit organisations from a waiting game to an effective mobilization. Such a statement raises some concern.

We can take for granted that non-profit organizations would support from expect public authorities. This is particularly true for those who work far from healthcare and humanitarian areas. Information released by governments will play a key role to set a climate of trust (or suspicion). Non profit organizations are often accustomed to work in partnership with public authorities. If an effective contribution had to be expected from them, it would depend on the availability of reliable information.

Today only associations involved in emergency care have set procedures for pandemic preparedness. We have assessed that 87 % of associations have never mentioned pandemic flu in the course of their internal debates.

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<sup>1</sup> 55 % of representatives answered that they own only weak information about pandemic flu, or no information at all. 41 % of them said that they are averagely informed.

Risk awareness is thus low. Some misbeliefs have been spotted. For example, some associative representatives think that the intensity of social mobilization will have to be proportional to the virulence of the virus strain.

Homeworking, communication through the Internet are sometimes mentioned as potential solutions. But we know that ill people (especially in hospitals) would need care. And care is concrete, not virtual.

Volunteer's mobilization seems to be mainly a matter of education, if we expect such mobilization to be relevant. A "pandemic culture" has to be spread.

Of course our survey has its limits. But some of the conclusions it brought are quite worrying. To be true, individuals accepted to respond our questions, not institutions. What is probably the most concerning is the fact that the potential consequences of a wide social disruption are often not even seen.

Whatever doubtful they can be about what the risk a pandemic flu would mean for our society, non-profit organizations have the key skills and people required to prevent social links to break. By "key people", we mean both volunteers and full-time workers. Who will be able and entitled to help whom? This interrogation was particularly raised about prisons. But we should extend its range by asking: will society margins have to help themselves overcome a flu pandemic?

Protection of both associative workers and volunteers who would be mobilized to face a pandemic is a major issue. It is not only a matter of access to antiviral drugs. It is rather a wide insurance problem. Mobilized people may lose their life. What kind of compensation is to be insured for non-profit organizations collaborators and for their families?

Considering the potential role of non-profit organizations leads us to tackle the wider subject of society preparedness. What do we expect to be done during the crisis and what sort of education and formation are we promoting to reach collective goals? How do we imagine the post-crisis phase? Today, in France, the expected operational role of associations to overcome a flu pandemic remains unclear. All we can call for is a deeper discussion within associations. If we do not make things clear on responsibility matters in the whole society, then it would just mean that a central authority would have to decide for everything. In every country, the issue of citizens and NGOs involvement must be questioned. This way, we will unfold the nature of the preparedness we are capable of.