Bruno Spire is a researcher living with HIV and a senior scientist at the French National Institute for Medical Research (INSERM). Bruno has been a member of the International AIDS Society (IAS) since 2008 and has been on the IAS Governing Council for the European region since 2016. Since 1988, he has been a member of AIDES, the main nongovernmental HIV organization in France, and he is now honorary President. Bruno is a scientist, but more so, he is an advocate on HIV community-based research. In this personal narrative, Bruno shares his experience connecting science and activism and how to apply that concept to the GIPA principles. This is his story...

From science to activism

The first time I went into a lab, I was a medical student interested in research. From the beginning, the research lab interested me more than the hospital. In 1981, I arrived in the laboratory of Jean-Claude Chermann, where Nobel Laureate Françoise Barré-Sinoussi was working. Two years before the discovery of HIV, they were studying retroviruses in mice, exploring the possible relationship between retroviruses and cancer. I opted not to return to the hospital and to continue working with them, which is why I became involved in HIV research from the very beginning.

This was a very exciting time for me, both professionally and personally. Suddenly, everyone was talking about homosexuality at work because of the epidemiology of the disease. I realized I was not the only gay man in the world, which is what I had thought before.

For the next several years, I worked between labs, finishing medical school and getting my PhD, but this career track started to bore me. It was around that time that I became a volunteer at AIDES, the main organization in France. AIDES was involving all kinds of professionals, as well as the people who were affected by HIV: the patients, and the people who were most exposed to HIV.

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And suddenly, in 1997, I became HIV positive myself. After the initial shock – because it’s always a shock – I decided, “now, I have to do what I really want to do”. So, I changed direction and through INSERM I was able to work for one year at AIDES. At AIDES, I set up projects, such as a university for people living with HIV; this was a self-support programme that allowed people to study HIV medication and adherence at the same time. This was at the very beginning of triple therapy, and a lot of people were finding it complicated; so my role was to support and convince people that it was important to take these drugs and to take them well.
At the time, many people in the community were not convinced by antiretroviral therapy and were quite reluctant to take these drugs, in part because there had been so much disappointment with monotherapy and double therapy. We had to change the way of thinking and convince people that this was a genuine revolution.

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After that experience, I actually returned to an INSERM lab – this time as a social scientist working with Jean-Paul Moatti, who was the head of a social science research unit in Marseille. I actually define myself more as a community-based researcher because I run my projects with community-based organizations in which lay stakeholders have a role in research. To elaborate further, I am defining lay people as individuals who are not necessarily academic by training, but who can discuss issues with their academic partner as equals because of their life experience. In my mind, lay people are a critical pillar in the AIDS response and the GIPA principles.

Revaluating the current GIPA principles

The GIPA principles are great. “Nothing about us without us” is exactly the right approach. What I don’t like is the way the GIPA principles have been applied. The idea that people living with HIV should always have their own organization is a kind of “ghettoization” of people living with HIV. To me, GIPA ought to mean that people living with HIV must have key positions in society. They should not be parked in specific roles or organizations. I think that it’s important to have community organizations of lay people who are concerned with HIV, organizations in which people living with HIV are equal to people not living with HIV.

The same applies for key populations and other affected populations. These populations include people with professional experience, training or personal insight and energy that could play a critical role in the response.

Unfortunately, what is happening now is that organizations of people living with HIV have limited to no role in delivering services to people living with HIV while other, well-resourced organizations do this work. Often, people living with HIV are not part of the professional staff of these implementing organizations.

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I think that we should have an alliance between people who have classical expertise and people living with HIV who have life expertise of HIV and who should have the political power to tell the experts what to do. We need to avoid the common tendency at the global level to divide civil society by continually drawing people living with HIV from organizations and, instead, empower people living with HIV to take power within the organizations that are actually running activities.

In my view, GIPA doesn’t mean that large organizations should make sure that on the side there is a small organization of people living with HIV who are occasionally consulted and asked what they think. GIPA means that people living with HIV should replace these large NGOs and actually become the principal agents for organizing the response. People living with HIV will never be able to do this alone, which is why it is important that we become united, including people with expertise. Ultimately, we should be focusing on uniting sero-concerned people. These include not only sero-infected but also sero-affected or sero-exposed people – all of whom have a personal reason to get involved in the response.

It’s not enough to have a designated seat at the table for any key population or person living with HIV. What matters is that that person also represents a group, not only themselves. With no movement behind them, this form of representation is just tokenism.
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GIPA 2.0

For me, GIPA 2.0 should include key populations and affected populations, and not only people living with HIV. We also need to have a more integrated version of GIPA in the real world – one that is not intended to create a kind of serological apartheid or even civil apartheid versus professional people, but to integrate lay people into conventional organizations. We need not only representation on the board, but also the power to run things in organizations. To take the IAS as an example, it’s not enough to have a representative of civil society in the governing council.

If we truly want to realize the GIPA principles in the IAS, we will have to take specific steps within the organization to bring lay people and scientists closer together.

As an example, the IAS Educational Fund meeting in Morocco was really successful, partnering with a Moroccan organization and with Coalition PLUS. This could be the model for moving forward. In all cases, we will want to choose partners that are community based, with a community spirit.