



The greater and more meaningful engagement of people living with HIV: Making the case for the HIV biomedical industry

During the 1994 Paris AIDS Summit 42 countries declared the 'Greater Involvement of People living with HIV/AIDS (GIPA)' a cornerstone of the HIV response. Since then, GIPA has catalysed a more nuanced understanding of how people openly living with HIV can and should influence the AIDS movement. From facilitating the involvement of people living with HIV (PLHIV) in developing national strategic plans to influencing the global AIDS architecture of the Global Fund and PEPFAR and shaping HIV service delivery and advocacy, GIPA has – in ways large and small – contributed to addressing stigma and discrimination.

Looking back, at its core GIPA means two things:

- The recognition that PLHIV have intimate knowledge of factors making people and communities vulnerable to HIV as well as first-hand experience of the realities of living with HIV
- The creation of meaningful spaces within every aspect of the HIV response to include PLHIV in decision-making processes that affect their lives.

Today, many stakeholders in HIV have found innovative ways to involve a diverse range of PLHIV and this has contributed to strengthened and improved responses. In particular, this has consistently highlighted the importance of acting on the links between HIV and human rights and set a high benchmark for PLHIV involvement and engagement across a range of disciplines. But on the eve of the IAS Conference on HIV Science in Paris, and grounded in the belief that the GIPA principle promotes and guides the substantial and meaningful engagement of PLHIV at all levels of the HIV response, it is opportune to consider how deeply and widely GIPA is understood and implemented. Is GIPA still as relevant and meaningful for all sectors in the HIV response today?

To take stock of the current implementation of GIPA across the HIV biomedical industry sector in particular, the IAS Industry Liaison Forum recently conducted a rapid survey on the opportunities and challenges of GIPA (1).

Primarily an external role

Besides the provision of capacity-building opportunities and grants to community-based organisations and the involvement of PLHIV as clinical trial participants, the HIV biomedical industry has primarily engaged PLHIV in external advisory roles (through 'community advisory boards' and informal discussions), typically in the context of research and development (mostly around clinical studies) and access programmes. This engagement has also followed the guiding principles of respect, mutual understanding, integrity, transparency, accountability and community stakeholder autonomy.

1. More than 200 people from 85 companies (prevention devices, diagnostics and drug manufacturers) were invited to fill a survey in January 2017. A total of 40 responses were received, spanning 13 countries and the areas of HIV prevention devices, HIV diagnostics and HIV drug manufacturing.

Our survey highlighted existing well-intentioned practices and opportunities that could be synergised:

1. *The insights of PLHIV are valued in various stages of clinical research:* protocol development (including informed consent processes and policies on trial-related harms), site selection, result dissemination, and post-trial access policies. PLHIV are also currently predominantly involved in developing and implementing access programmes, mainly around HIV treatment. Finding appropriate avenues to more actively engage PLHIV in other areas is an subject for deeper exploration.
2. *The HIV biomedical industry are interested in taking GIPA further:* People working for the HIV biomedical industry are also hoping to expand how they involve PLHIV in their business and to learn how to do so. This provides a unique opportunity to scale up a more systematic GIPA engagement by strengthening the working relationship between the various national, regional and international PLHIV networks and the HIV biomedical industry.

Moving beyond an external role

People openly living with HIV as 'internal' resources is highly relevant in specific areas of the HIV response. Such involvement can move PLHIV from external to internal contributors who are fully recognised as integral to the organisation, empowering them and further helping to reduce stigma and discrimination. In addition, this can also contribute to better-informed and executed projects across the industry, with positive repercussions both at the HIV response and business levels.

However, our findings showed that PLHIV are mostly engaged as external contributors, and often through the lens of corporate social responsibility. Unfortunately, GIPA often seemed limited to this type of engagement, which did not include open engagement in the workforce. Fully embracing this more modern interpretation of GIPA is particularly important given the nature of this industry, which is involved in developing and manufacturing commodities specifically for the HIV response. There are undoubtedly many people living with HIV who are working in the biomedical industry today. Their decision to not reveal their status must be respected and upheld at all times. But simultaneously corporate HIV workplace policies and programmes should more actively build an environment where disclosure (if desired) is supported and where opportunities are created. It is in ways like this and through staff sensitisation that the more meaningful engagement of people *openly* living with HIV in the biomedical industry can be strengthened.

Making GIPA relevant one sector at a time

Of the more than 37 million PLHIV today, the majority are of working age. PLHIV are in every circle of society irrespective of their decision to disclose or not their HIV status. Meaningfully engaging people openly living with HIV in the HIV biomedical industry workforce can contribute to the development of better-adapted products. Our survey findings demonstrate existing engagement of PLHIV as external advisors and the interest of individuals involved in the HIV biomedical industry to do more. PLHIV networks should reach out to HIV biomedical companies – involved in the prevention, diagnostics or treatment businesses – located in their region. The biomedical industry should also review their HIV workplace policies and programmes through a GIPA lens for the majority of our survey respondents believed meaningfully engaging PLHIV today remains relevant and can represent a positive asset to the HIV biomedical industry. It is time to transform this willingness to do more into actual involvement, one sector at a time.