Role of community-based research in advocating HCV prevention and care

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Received 14 August 2017; Accepted 22 August 2017

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In their article, Grebely et al [1] clearly present how criminalization and stigma are still the main barriers to hepatitis C virus (HCV) prevention and care for people who inject drugs (PWID). The authors provide perspectives and ways forward to overcome these barriers. They also suggest that taskshifting prevention and care for these groups to community services can be more effective and improve the HCV cascade, as these measures attract most-at-risk populations, thanks to reduced stigma.

However, the authors do not mention another important and effective approach: community-based research. This approach can help to reduce stigma, advocate equity in healthcare and promote change in health policies.

The basic principles of community-based research are well known. The first is doing with people, not for people. This means that research is based on the mobilization of concerned groups utilizing a bottom-up approach, and relies on the expertise of persons living with the disease.

Communities have the power to promote policy and social change. Community-based research is very effective as its arguments to endorse social transformations are based on real-world evidence.

There are several important examples of how community-based research has contributed to change health policy in France. These include ANRS DRAG, which promoted community-based testing as a tool to attract most-at-risk groups [2], ANRS Ipergay, which showed the effectiveness of on-demand HIV pre-exposure prophylaxis on HIV incidence in MSM [3], and ANRS AERLI, which evaluated the effectiveness of an existing educational intervention entitled AERLI for HIV and HCV prevention in PWID [4,5].

More specifically, ANRS AERLI was implemented through a collaboration between the French National Institute of Health and Medical research (INSERM) and two community-based associations AIDES and MDM, to respond to a specific public health need which was to identify and evaluate innovative harm reduction and HCV preventive interventions. One such existing intervention, called AERLI, was community-based and focused on reducing injection-related harm. Conducted by peers and other health staff, it was based on two nested phases: the use of a standardized checklist when supervising injection and a tailored intervention to reduce harm which included information about hepatitis C testing and treatment.

The ANRS AERLI study showed a significant reduction in HCV risk practices and an increase in HCV testing in the intervention group [4,5]. The importance of these results led AERLI to be included as a novel prevention intervention in the new 2016 French health law. This intervention will be now scaled up and replicated in several contexts, such as needle exchange programmes, safe-injecting facilities and outreach programmes. Its effectiveness will also be evaluated in different European countries. Like needle, syringe and opioid maintenance treatment programmes, AERLI will be used as a new entry point for hepatitis testing and treatment.

In conclusion, if we really aim to “leave no one behind” in the field of HCV, then conducting research with affected communities must be adopted as a complementary approach to reduce inequalities in prevention and care, to advocate changes in health policy and more importantly, to act against criminalization and stigma.

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COMPETING INTERESTS

The authors have no competing interests to declare.

AUTHORS’ CONTRIBUTIONS

PC wrote the first draft of the letter and revised it until the final version. PR contributed to the revision of the letter until its current version.

ACKNOWLEDGEMENTS

We acknowledge ANRS for funding the ANRS AERLI study and Médecins du Monde et Aides Association for conducting and contributing to the ANRS AERLI study. We also acknowledge Jude Sweeney for the English revision of the manuscript.

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