

**Those who are not seen are not heard – a commentary on “Optimising the Impact of Key Population Programming Across the HIV Cascade,” a supplement in the *Journal of the International AIDS Society***

**By Gus Cairns**

“What is not measured is not managed,” business guru Peter Drucker said. That axiom applies with force to the Key Affected Populations (KPs) in the HIV pandemic. We cannot devise evidence-based HIV programmes for populations of men who have sex with men, transgender people, sex workers, people who inject drugs, prisoners and displaced people, if we do not know the size of those populations, how many have HIV and how many are at risk, and what their treatment and prevention needs are.

In July of last year, the *Journal of the International AIDS Society* published a [supplement](#) dedicated to advancing key population-focused science and practice across the HIV prevention, care, and treatment cascade. This supplement contains a number of examples of successful work with key populations, all of which point in the direction of how to further their good work and turn it into widely-used programme components. Some of these steps are very simple, and ones that could have been applied at any time during the history of the epidemic, had the political will been there. It is encouraging now, however, that the needs of previously invisible or denied people are being acknowledged and programmes to test, prevent and treat HIV are being especially directed towards them and tailored to their particular needs.

**Those who are not seen are not heard**

Unlike Drucker, we are talking about human beings, not sales figures; people, who may be able to articulate their needs personally, had they the chance. So it might be simpler and more truthful to say: “Those who are not seen are not heard.”

There are good reasons why those populations and their needs are not measured. Or, rather bad reasons: reason of stigma, self-stigma, denial, fear, violence, imprisonment and ill-health both physical and mental.

**Surveillance is key**

To put it a third way, those who are not sought are not found, and key populations are often not just invisible but invisibilised: in some cases, as with men who have sex with men (MSM) in many countries, to admit and research their very existence is confrontative to many cultures.

One study in this supplement that describes this invisibility is from Dakar, Senegal (Mukandavire). Here, evidence from three Behavioural/Biological Surveys, fed into a model of the local epidemic, has found that MSM are not only a key population for HIV infection but numerically *the* key population. Yet MSM, as the authors acknowledge, have been simply left out as a population group in previous surveys in west Africa, perhaps due to cultural assumptions about the non-existence of homosexuality there.

**Targeting your general population may exclude your key populations**

The second paper in the supplement (Hakim) spells out one consequence of such assumptions. One of the few countries that has compared prevention behaviour in their

general population with their key populations is Mozambique. Here, surveys (conducted in different years) found lower rates of HIV diagnosis and treatment in key population members than in the general population. In 2016, a third of the general population were diagnosed and three-quarters of those on ART. But surveys from 2011-12 found less than a quarter of female sex workers and less than 9% of MSM diagnosed and no more than half of those on ART.

### **Use the internet's 'e-communities'**

How one reaches and meets the needs of the previously unreached varies from population to population. MSM worldwide have taken to the internet as their "e-community": the way they prefer to contact each other. One study from Thailand (Phanupak) found more than half of MSM and transgender women spend over four hours a day online.

Among key populations that have access to the internet, this offers considerable opportunity for self-empowering health education and support. In the article presenting results from "Blue Ribbon Boys" survey with Hornet app users (Ayala), it is notable that PrEP use was quite high at 13% among the HIV-negative participants, and ART use in HIV-positive ones two times higher in men who had heard that viral undetectability leads to untransmissibility of HIV ("U=U"). These are messages likely to be learned and reinforced through peer-to-peer discussion on social media.

### **Self-testing may be safer testing for key populations**

A community that spends a high proportion of its time in the virtual world may prefer its HIV services to be offered through the net and in private, too. Two studies in Nigeria (Tun) and Vietnam (Green) found considerably higher HIV case-finding from MSM self-testing for HIV than have been seen in clinic-based testing – in the Vietnam study, 11% of those who were reached online and self-tested had HIV compared with 1.6% in clinic testing. Fears that self-testing might not result in HIV-positive testers being linked to care appear unfounded from these studies, with 93% of those diagnosed in the Vietnam study linked to care, and all of them in the smaller Nigerian study.

In the Nigerian study, self-test kits were often 'cascaded' down to other friends and family members, and something of a culture of testing together was established. This echoes findings from a previous study in South African MSM.<sup>1</sup>

### **Meet people where they are**

Not all key populations can network online, however, especially if they are highly criminalised and fear identification. People who inject drugs and sex workers, and MSM in countries with severely repressive policies or simply no internet access, may still need to meet in physical locations or networks, and these locations often present opportunities for engagement, as in the study of the PLACE methodology used to reach cis and trans female sex workers in Malawi and Angola (Herce).

The necessity of continuing and intensifying such outreach programmes is underlined by the fact that even though a relatively high proportion of study participants had tested for HIV at

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<sup>1</sup> Lippman SA et al. High acceptability and increased self-testing frequency after introduction of HIV self-testing and network distribution among South African MSM. JAIDS 2018 77(3):279-287.

some point in the past, a large number of people tested HIV positive, and in Benguela in particular, the vast majority were unaware of their infection. In the study of people who inject drugs in Tajikistan (Kun), respondent-driven sampling was found to be the best way to contact a population not yet infected, but possibly at imminent risk of HIV that could become the first wave of cases in a new local epidemic, with relatively low HIV prevalence but high rates of needle sharing.

### **The power of peers**

But online and in-the-home services can only go so far. There comes a point when visiting a welcoming facility is necessary, not so much because medical monitoring and prescribing cannot be offered otherwise (they can, as task-shifting to community-based health cadres and home-based services show), but more because people need to 'learn the ropes' and feel empowered to ask for the services they need.

In many locations, engagement with care rather than testing is the step at which people are most likely to fall out of the 90/90/90 care continuum, and it is at this point rather than during the testing process that support from an experienced mentor may be most necessary.

The article describing the results and recommendations from key population-focused cascade assessments in several countries (Lillie) suggests that this support may be found in the form of peer navigators, HIV-positive volunteers or workers who already know the system and can quite literally steer people to healthcare centres.

### **Train all your staff in their patients' needs...**

Peer navigators can also help negotiate with healthcare staff. Another theme that often emerges in these kinds of assessments is that patients complain of discriminatory, moralistic or ignorant treatment by healthcare staff – not so often doctors as ancillary staff. Over ten per cent of participants in the Thai self-testing study who answered a question about stigma in healthcare settings had experienced it to the point of substandard services or, in a third of cases, denial of them. Sensitisation training of all cadres of staff involved in HIV care in centres and in outreach programmes is a vital part of offering services that key populations members will wish to return to.

So, while outreach is vital, people also need to be linked to HIV and sexual health care, and a sensitive, knowledgeable and friendly reception by healthcare staff is a vital enabler of linkage to and retention in care. Lack of it may frighten people off testing altogether: MSM in the Thai study who had experienced discrimination by healthcare workers were actually significantly *less* keen on home testing, possibly because they felt it would not help them assert their healthcare needs in the event of a positive result.

### **...and patient loyalty will follow**

One of the most successful programmes documented in this supplement links the Sisters with a Voice national programme for female sex workers in Zimbabwe with rises in condom use with steady partners, recent testing, HIV diagnosis, engagement in care, and ART prescription – most of the steps needed to improve the 90/90/90 cascade.

It is significant that during the four years of the study – 2011-2015 – the most frequent access point for condoms changed from local hospital clinics to the Sisters clinics. This simple statistic speaks of the centres providing what the women needed, and time and

again studies have shown that when centres offer resources that key populations can use in health and risk self-management, 'customer loyalty' will develop.

The history of the epidemic has shown us time and again that if members of key populations are persecuted and criminalised, and if their HIV prevention and treatment needs are neglected on the basis that only the deserving should be cared for – then that is when the conditions are set up for an expanding HIV epidemic. If engagement means exposure – to the police, to vigilantes, or to client or dealer violence – then, unless safe spaces are set up in which their needs are recognised, an easy-to-reach patient may become a hard-to-retain one.

### **Take stigma and violence seriously**

It is important that the supplement ends with two papers about stigma and its most severe expression, violence. The paper on the Stigma Index (Friedland) found that in Senegal especially, while stigma against people with HIV in general was lower than it was in other countries, the rates of stigma faced by key populations was higher.

One particularly important finding is that members of key populations, especially MSM, trans women and sex workers, encountered high levels of sexual violence, which can be both a cause and a consequence of HIV infection and can also serve as a disempowering life event in itself. More than half of survey participants from Cameroon had experienced sexual violence and 41% from Senegal. Nor is this the only paper that mentions forced sex: in the relatively more sophisticated setting of Thailand, in the Phanupak paper, nearly a quarter of MSM and half of trans women had experienced sexual violence in the last 12 months.

Sexual abuse, both experienced by adults and also by those adults as children, and intimate partner violence in general, is one of the individual factors most strongly associated with HIV diagnosis and with failure to engage in care, and it is encouraging to see a paper about a programme in Kenya (Bhattacharjee) that has resulted in more FSWs and people who inject drugs reporting incidents of violence and of incidents being investigated – though the same increases have yet to be seen among MSM.

### **Blind spots: who is NOT being seen?**

Finally, one cannot comment on a selection of studies describing progress and contributing new evidence for key population programmes without mentioning key populations and regions that are not covered here and speculating whether this reflects wider gaps in research. *Lack* of research may be the indicator of populations that are being stigmatised to the point of invisibility - one possible example being MSM in eastern Europe and central Asia.

Another reason key affected populations are under-researched may be because they are by definition hard to track. One example is newly-arrived migrants, a group who are, as some studies have shown, at high risk of HIV in their host countries, but whose characteristics, behaviours and needs may be hard to establish.

Conversely, if populations are researched, their prevention needs analysed, their medical needs addressed, and the multiple needs that prevent them from using prevention and turn them away from treatment are met, then really significant reductions in HIV incidence, even among the most apparently vulnerable people, can be met.