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Factsheet 9
The benefits of focusing on and mobilising with key populations

This factsheet provides information on the importance of testing for HIV and/or hepatitis amongst key populations, as opposed to the general population, and how to work with key populations in achieving the common goal of increased uptake of testing and treatment.

Glossary of terms used in this document:

At-risk populations: Defines groups of individual people who statistics show are most susceptible to contracting HIV and/or hepatitis. Please note that this type of language is not often used on the ground by communities, but rather, used across international NGOs, support groups and healthcare bodies

Key populations: Defined groups who, due to specific behaviours, are at increased risk of HIV irrespective of the epidemic type or local context.[1] As a group, key populations are disproportionately affected by HIV and/or hepatitis

What are the key populations?

Higher vulnerability of key populations to HIV and many other illnesses (e.g. hepatitis) can result from social and structural factors, including criminalisation, discrimination, stigma, violence, social and economic marginalisation and/or exclusion to which they are often subjected. Key populations can also have legal and/or social issues that increase their vulnerability to HIV and/or hepatitis.[1] Examples include unprotected sex, sex work with low condom use and people who use drugs and lack access to sterile injecting equipment. Key populations in relation to HIV are identified by UNAIDS and WHO as gay men and other men who have sex with men (MSMs), sex workers, trans people and people who inject drugs (PWID). [1,2] These groups are affected by a high risk of contracting and transmitting HIV/hepatitis.[3]

In many low and middle-income countries, key populations face HIV prevalence rates that are 15-25% higher than the surrounding general populations. It is therefore crucial to identify the most effective way possible to engage key populations in sharing knowledge and education around the importance of HIV and hepatitis testing.[4]

Key populations include:

- Men who have sex with men (MSM)
- Sex workers
- People who inject drugs (PWID)
- Amphetamine-type stimulant (ATS) users/injectors
- Migrants, including people originating from high prevalence countries and mobile populations
- Trans people[5]
- People in prisons and closed settings

Additional key populations for hepatitis

- People on long-term haemodialysis
- People who have received blood
- Recreational drug users
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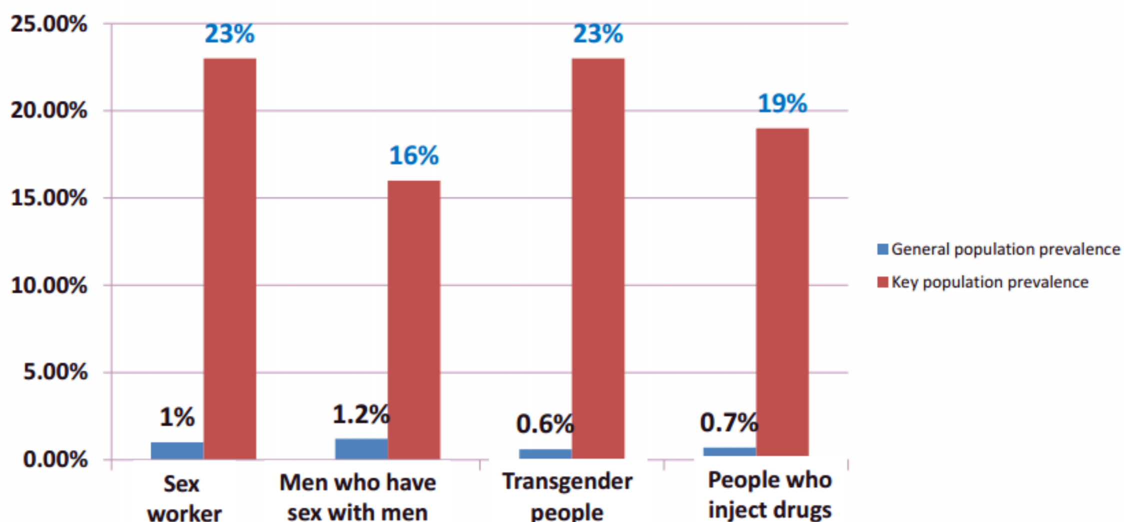
Figure 1 below, shows the prevalence of HIV infection amongst key populations globally, when compared to the general population*. With the infection rate in some cases being 20 times that of the general population, this provides sound evidence for engaging with and mobilising key populations appropriately.

Figure 1. Global prevalence of HIV infection amongst key populations (Based on 88 countries from 2007 -2013)[6]



*General population varies in the graph depending on the country and year the study took place

Why are key populations at greater risk of HIV/hepatitis infection?

In appendix one, you can find facts for each of the UNAIDS and WHO identified key populations, which provide evidence around why these populations in particular are at greater risk of HIV/hepatitis infection. These statistics can be adapted for use in your own country.

In what ways do stigma and discrimination contribute to an individual's vulnerability to HIV/hepatitis?

Aspects related to peoples' identities, behaviours and sexualities could make an individual more vulnerable to HIV/hepatitis and might increase their risk of acquiring the viruses. Additionally, many key populations face stigma and discrimination.

Key populations can be subject to stigma from family, communities and health workers, health organisations and law enforcement services;[7] this can lead to delayed HIV/hepatitis testing, concealment of a positive status and poor uptake of HIV/hepatitis services. It can also undermine the efforts of national health programmes to effectively link people to HIV/hepatitis care and to engage and retain them in long-term care.[7]

Further to this:

- Laws that criminalise sex work, same-sex sexual acts and relations, drug possession and drug use, undocumented migrant status, etc., can often fuel the social intolerance and discrimination that key populations endure. This can drive them underground, making it difficult for them to access essential social services like HIV/hepatitis prevention and testing, treatment and care and health information/education
- Violence against key populations including migrants and refugees, sex workers, drug users, trans people, gay men and other MSMs has been shown to be a risk factor for HIV and can include physical, sexual or psychological violence
- Harsh laws, policing practices, cultural and social norms can contribute to the violence experienced by key populations, as well as add to the stigma and discrimination they face

Why focus European Testing Week activities on key populations?

Testing for HIV has costs associated with it. In 2011 the Health Protection Agency's report '*Time to test for HIV: Expanding HIV testing in healthcare and community services in England'* found that the cost per test conducted within the pilots ranged from £3 - £12 in hospitals settings, from £6 - £8 in primary care settings and from

£21 - £47 in community settings. In their research they identified that the majority of the highest positivity rates were reported in community-based projects amongst key populations.[6]

With limited resources, HIV testing and care need to focus on the smartest investments and thereby focus on testing in populations that are most affected by HIV/hepatitis and frequently face severe barriers in accessing health care services. Targeted testing in this way will produce a higher ratio of those testing positive, allowing them to enter into an appropriate treatment and management pathway for their HIV and enabling them to gain evidence-based knowledge on minimisation of transmission.

The Health Protection Agency recommend community HIV testing services need to be appropriately targeted and established with strong community representation, including involvement, meaningful participation and leadership. To be successful these initiatives require long term financial and political commitment and empowerment/meaningful involvement of key population communities and networks (see factsheet 8 – How to reach Government bodies).

What is community mobilisation and empowerment?

Community mobilisation and the process of community empowerment is, by definition, driven by the community themselves. It can allow a diverse group of people to come together and form a network, who may not be used to being involved in a decision-making process, to achieve goals that are important for their community.[8]

It is therefore impractical to adopt a prescriptive, inflexible approach to implementing community empowerment initiatives. Some groups representing key populations throughout the world have identified some key elements of community empowerment, which can be translated across various key populations (see Figure 2 for an example).

Community mobilisation is not something that is done overnight, but it is a process that requires time and commitment from all parties involved. The key to successful mobilisation efforts is making sure that communities are:

1. **In the driver's seat during the process.** This allows a community to solve its problems through its own efforts which is the key to having sustained outcomes within a community.
2. **Supported with tools.** The community may not have all the tools available to support them and these can be provided in the form of knowledge, resources, support, empowerment and leadership skills, to name a few.

Figure 2. Key elements of community empowerment among sex workers[10]

Mobilisation is not something that happens to the community; it is something that the community does. It should be supported and recognised as the most effective response to HIV and/ or hepatitis.

Mobilising key populations to advocate for HIV/hepatitis testing

Community empowerment and involvement of key populations should be a key focus of HIV/hepatitis testing and other patient advocacy activities that aim to facilitate supporting key populations and increase access to an uptake of HIV/hepatitis testing.

Both the London School of Economics (LSE) and World Bank research revealed that community mobilisation is vitally important in the achievement of long-term HIV and health outcomes, in particular reaching people most affected by HIV and changing social norms and practices.[9]

How could you help to mobilise key HIV/hepatitis populations?

Collaboration between HIV/hepatitis organisations and organisations that provide services to, are accessible by, or are led by key populations, is a good starting point

to mobilise the community to advocate for testing. In addition, there could be collaboration with key population networks that advocate for rights-based services – which include HIV and/ or hepatitis testing services.

Working with key population-led and community-based organisations and networks is beneficial, as they are best placed to reach key populations quickly and effectively using the best tools, approaches and languages that the community will respond to. For example, supporting or linking up with organisations that support sex worker rights or outreach groups who have existing contact with sex workers to provide education on HIV/hepatitis testing with their clients may be more effective than your organisation delivering the training to them (e.g. The International Committee on the Rights of Sex Workers in Europe (ICRSE)). This is because trusted lines of communication will already exist between the sex workers and the outreach groups, particularly where they are sex worker-led projects.

To do this we recommend you conduct a key population organisation 'mapping' exercise in your local country (see Toolkit 4 - Engaging with other partners). Once you have identified the most influential key population organisations to partner with;

- **Inform** them what testing week is and how important it is for their communities to be tested so that they can work with you to educate the key populations appropriately. Collaborative working arrangements are key to successful campaigning, ensure your conversations are two way; informing partners of the role they can play, and partners informing testing week how best to work with them to reach a united goal
- **Invite** them from the very beginning to get involved and contribute to the success of testing week - partners will be able to help across all stages to evolve testing services
- **Let them know** you would like to work together to listen to their needs and know how to work together to reach key populations and increase testing rates amongst their communities

Key population organisations, campaigns and interventions you may wish to consider

Below we have included some key population organisations and institutions you may wish to consider as part of your stakeholder mapping and possible testing week campaign approaches and channels to use. Additionally, we suggest considering

evidence-based interventions such as Peer Driven Interventions, or Social Network Interventions. Many have been proven successful reaching high risk individuals, connecting them to treatment and minimising or eliminating risk behaviours causing HIV/HCV infections.

Key HIV/hepatitis Populations	Key population organisations and campaigns you may wish to consider
Men who have sex with Men (MSM)	• Identify gay organisations and influencers • Hold an advisory board to identify appropriate materials and access channels • Agree campaign to roll out in partnership with gay community • PRIDE related events
Sex workers	• Identify organisations that support sex worker rights or outreach groups who have existing contact with sex workers as part of your stakeholder mapping • Work with identified sex worker-led and non-sex worker-led service providers support organisations to roll out testing week in this community • Engage sexual health services and clinics
People on Haemodialysis	• Consider identifying kidney charities as part of your stakeholder mapping • Reach out to kidney disease charities around partnership campaigns for testing week • Channels could include a testing week campaign on websites
Migrants	• Identify national and international immigration charities to partner with • Have the right conversations with the right people – consider an advisory board meeting • Work with migrant charities / engage with migrant communities and migrant-led organisations to roll out the campaign as they can reach the right networks and you

	can provide the right information around testing
People in prisons and closed settings	• Consider including ex-offender support networks and organisations and homeless charities when mapping out your stakeholders for this population
People who inject drugs (PWIDs)	• Consider engaging harm-reduction programmes to help shape your activities with and for PWIDs
Trans people	• Identify international, national and local trans people organisations or groups for your area • Do an online search for trans people + HIV + hepatitis • Share your research with your colleagues

Appendix one

MSM

- Homosexuality can be oppressed in some countries, which means MSMs are at higher risks of HIV infection due to being forced 'underground' and having less access to health information and care[11]
- More than half of people newly diagnosed with HIV in 2014 were men who have sex with men[12]
- Prevalence of HIV among men who have sex with men in [insert country] is on average [insert statistic] times greater than in the general population
- Prevalence of hepatitis among men who have sex with men in [insert country] is on average [insert statistic] times greater than in the general population

Sex workers

- Sex work is still criminalised, penalised and legally oppressed in most countries. Harsh laws and policing frequently forces sex workers underground to precarious and unsafe working settings. Sex workers face many obstacles in obtaining HIV prevention and care such as stigma, discrimination, criminalisation, violence, and poverty[11]
- Globally, the average HIV prevalence among sex workers is estimated to be approximately 12% and in countries with medium and high HIV prevalence in the general population, 30.7% of sex workers were living with HIV[1]

- Prevalence of HIV among sex workers in [insert country] is on average [insert statistic]
- Prevalence of hepatitis among sex workers in [insert country] is on average [insert statistic]

People in prisons

- HIV infection rate is high among prisoners due to harsh prison conditions. Overcrowding, sexual violence, drug use and lack of access to HIV prevention commodities such as condoms and lubricants means transmission risk is very high
- There are more than 10 million men and women in prisons and other closed settings. Globally, the prevalence of HIV, hepatitis B and C and tuberculosis in prison populations is estimated to be twice to ten times higher than in the general population[1]
- Prevalence of HIV among prisoners in [insert country] is on average [insert statistic]
- Prevalence of hepatitis among prisoners in [insert country] is on average [insert statistic]

PWID

- Criminalisation, harsh policing practices and inaccessibility of sterile injecting equipment tends to make HIV and hepatitis prevention and treatment particularly difficult for people who inject drugs[11]
- In 2012 worldwide around 12.7 million people recently injected drugs and of these, 1.7 million people (13.1%) were living with HIV[1]
- The estimated global prevalence of hepatitis C among PWID is 67% and 2.2 million HIV and HCV co-infections of which half are among PWID
- Prevalence of HIV among PWIDs in [insert country] is on average [insert statistic]
- Prevalence of hepatitis among PWIDs in [insert country] is on average [insert statistic]
- Prevalence of increasing HIV/HCV infections is seen among stimulant drug users at [insert statistic] (EMCDDA)

Migrants

- Migration can create complex obstacles, such as a lack of access to health-care services or social protection and social exclusion[13]

- There are approximately 231.5 million international migrants and 740 million internal migrants[13]
- For most countries in the Western part of the EU the proportion of migrants with HIV is between 20% and 40%[14]
- Prevalence of HIV among migrants in [insert country] is on average [insert statistic]
- Prevalence of hepatitis among migrants in [insert country] is on average [insert statistic]

Trans people

- Trans people are often subject to brutal law enforcement practices, arrests and incarceration and sometimes the violence perpetrated against trans people
- Trans people have a disproportionately high rate of HIV, but do not receive adequate access to medical treatment due to harsh stigma and discrimination[11]
- Among 7197 transgender women sampled in 10 low- and middle-income countries, HIV prevalence was 17.7%[1]
- Prevalence of HIV among trans people in [insert country] is on average [insert statistic]
- Prevalence of hepatitis among trans people in [insert country] is on average [insert statistic]

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