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The uncounted: politics of data and visibility in global health

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ABSTRACT
This article explores the political and economic factors that are driving shifting data in the context of HIV. In order to measure progress towards the Sustainable Development Goal (SDG) 3.3 on health, global health agencies such as UNAIDS, the Global Fund to Fight AIDS, TB and Malaria, and PEPFAR all rely on HIV data routinely reported by countries. This data is not produced in a political vacuum. Key populations vulnerable to HIV (men who have sex with men, people who inject drugs, sex workers and transgender people) are often hidden due to stigma and criminalisation. However, the absence of this data creates a paradox in which invisibility reinforces invisibility. Key population size estimates are a central tool for planning and resourcing national and global HIV programming, but these become hard to obtain when key populations are hidden and political leaders deny their existence. Pressure from health financing agencies is changing these power dynamics in some countries. Key populations who participate in these consultations question size estimates, interrogate the politics of HIV data, and demand that studies be more inclusive, ethical and attuned to their human rights. In the fight against HIV, data a critical stake in the struggle.

KEYWORDS
HIV; data; global health; development

Introduction: Key populations and the data paradox

The offices of frontline HIV/AIDS organisations can sometimes be hard to find. In Hong Kong, for instance, I walked through a cavernous airport-terminal-turned-mall for an hour before finding, behind a used car showroom, a small sign reading ‘Activity Center’. The programme director explained her organisation had chosen this vague sign to protect their clients from stigma. In Kingston, Jamaica, an HIV clinic was similarly located in an unmarked residential building. In Lilongwe, Malawi, my taxi driver circled leafy suburban streets asking several passers-by until we found a national HIV and human rights group. The compound gate had no sign, not even a street number. The organisation had moved there after a raid on their previous office.

Why do frontline organisations still have to hide, 30 years into the history of AIDS? Their work is essential for the HIV response, but for a number of reasons it is difficult for governments to support openly. The stigma surrounding HIV remains profound, especially for criminalised populations such as sex workers, men who have sex with men, transgender people and people who inject drugs. For these groups most vulnerable to HIV, whom the
World Health Organisation (WHO) calls 'key populations', visibility is dangerous. Exposure can lead to the loss of jobs, expulsion and eviction, extortion, arrest, police abuse, even death.

Organisations like those I visited in Hong Kong, Jamaica and Malawi, who aim to reach key populations with HIV services, are thus also forced to navigate their visibility carefully. The danger is increasing in a growing number of countries, where closing civic space and political scapegoating limits the ability of many organisations that represent or work with key populations to register and function: for example, the director of Labrys, an LGBT centre in Kyrgyzstan, vividly described how, after a firebombing of their office drove them out, his group held their small dinner for International Day Against Homophobia and Transphobia at a quiet restaurant, but were still attacked by nationalist thugs. The absence of signage, the careful negotiation of public space, the use of coded language, all have to be understood as markers of absence, and of violence. Few people hide from their neighbours by choice. But many ‘uncounted’ key populations avoid being pinned down to the page, and skirt the traps set by numbers and names.

Yet this need to hide is in tension with a need to be reached with life-saving health services, in the context of high rates of HIV. As Baral and Greenall argue, key populations suffer from a data paradox: ‘Decision-makers deny that most affected populations exist … so no research gets done on these populations; the lack of data feeds the denial; and so on.’ As a result, though the Joint UN Programme on HIV and AIDS (UNAIDS) notes that key populations have higher risk of HIV in every geographic region, they have less access to prevention and treatment services.

In adopting the Resolution that approved the 17 Sustainable Development Goals, the UN General Assembly pledged that: ‘As we embark on this great collective journey, we pledge that no one shall be left behind …. And we will endeavour to reach the furthest behind first.’ Goal 3 commits to ‘Ensuring healthy lives and promoting well-being for all at all ages’, and SDG 3.3 aims to ‘end the epidemics of AIDS, tuberculosis, malaria, and neglected tropical diseases and combat hepatitis, water-borne diseases, and other communicable diseases’.

But the real world in which these commitments are funded, implemented and measured is rife with barriers that make estimating the size of the ‘furthest behind’ populations – a first step in studying, planning and resourcing national health responses, including the share of national resources funded by global health financing mechanisms – a challenging task. National health agencies often lack data on HIV prevalence, incidence, testing rates and coverage with prevention and treatment services among the very populations most vulnerable to HIV. As UNAIDS notes in its manual on HIV population size estimation:

- data are unavailable
- the basis of the estimates is not clear
- inconsistencies between estimates are not explained
Arguments to implement prevention, care and treatment programmes are more compelling when good estimates of sizes of at-risk populations are available.8

As the UNAIDS manual also acknowledges, the problem is not only that key populations hide, but also that governments ‘find it politically challenging to invest in services’ for them.9 The rhetoric of denialism is part of official narratives: ‘We don’t have homosexuals like in your country’, as Iranian President Mahmoud Ahmadinejad famously said to a US audience, even as Iran accepted international aid for its HIV programmes.10 In Uganda, the acting minister for health argued: ‘People know that homosexuality is not [a] Ugandan or an African issue. It’s [a] few individuals here in Kampala who are practicing and trying to promote it.’11

In some cases, governments attempt to re-negotiate the WHO definition of ‘key populations’; as a former senior human rights advisor at the Global Fund to Fight AIDS, TB and Malaria (the ‘Global Fund’), when reviewing funding requests submitted by countries to the Global Fund, I sometimes saw governments arguing for a more ‘culturally appropriate’ national definition of HIV-affected key populations that included less-controversial groups (long-distance truckers, fisherfolk) but excluded those identified by WHO: gay men, transgender people, people who inject drugs and sex workers. Recently, this push-and-pull over language reached the global stage: at the UN High Level Meeting on HIV and AIDS in July 2016, where UN member states gathered to approve the new global HIV strategy, a group of countries successfully pushed to remove numerous references to key populations from the strategy; and blackballed twenty-two LGBT, drug user and civil society groups that represent people living with HIV from the meeting.12

The result of this push-and-pull between moral discourses, law enforcement, and public health evidence, is a ‘data paradox’ in which politically sensitive research is not done on key populations, and ‘the lack of data feeds the denial’ that key populations have a right to health services.13 Services for key populations are in many countries driven and sustained by international funding, and the lack of domestic support for work to reach them is exemplified by the fact that in countries where international health financing mechanisms provide the main or only source of support for key populations programming, donor withdrawal as the country income level improves can result in a sharp uptick in HIV among key populations.14

Quantitative data has become contested terrain in a political debate over who counts, who does the counting, and who gets counted in global health governance. The SDG on health and related HIV targets have created an imperative to produce more, and better, health data in order to demonstrate progress. The pressure on health aid agencies to demonstrate impact of investments has fuelled this demand for increasingly granular data about HIV-affected populations, even down to the level of mapping the precise locations where those populations gather, and using biometrics to track individuals. However, for those most vulnerable to HIV, the fact of being studied poses complex challenges and risks. Anthropological and human rights literature critical of the use of indicators have tended to emphasise the normative, top-down power of indicators like the SDGs in shaping local responses to global governance.

Reporting against SDG 3.3 towards the ‘end of AIDS’ will be driven by data gathered and reported to UNAIDS, which receives routine reports from countries and uses them to measure progress towards specific targets on HIV. Furthermore, health financing agencies
will be deeply invested in producing and evaluating the data. States have the responsibility to fulfill the right to highest attainable standard of health for all citizens, including key populations. However, the extremely high cost of antiretroviral treatment and related care makes it impossible for many lower-income and lower-middle-income countries to fulfil that right without financial support from wealthier countries. The Maastricht Principles on Extraterritorial Obligations of States in the Area of Economic, Social and Cultural Rights have articulated the obligation of states to ‘take action to fulfill economic and social rights of persons within their territories and extraterritorially’, through inter alia, financial assistance. As a result of rights-based campaigning over decades by people living with HIV and their allies, significant infrastructure exists to finance the HIV response.

Thus, global health aid institutions also play an outsized role as political actors in the world of HIV. The programmes, data and capacity to gather and report on the data is underwritten by global health financing mechanisms, especially the Global Fund to Fight AIDS, TB and Malaria (‘the Global Fund’) and the US President’s Emergency Programme for AIDS Relief (PEPFAR). The Global Fund and PEPFAR, in partnership with UNAIDS, are collectively pressing for more and better data to both facilitate more granular programming and to demonstrate measurable progress towards the ‘end of AIDS’, the goal set in SDG 3.3. I argue that in the context of HIV, in which affected communities have long demanded a seat at the governance table, quantitative methods and measurements linked to SDG 3.3 are becoming a site of active contest. HIV-affected key populations, while frequently hidden for security reasons, also assert a human right to participate in and approve the methods and results of quantitative research about them. In the political field that makes up the global HIV response, data is a critical stake in the struggle.

The article draws on recently published data and UN and NGO reports, as well as on personal experience, to explore the tensions around these issues. My experience, which informs this argument, includes founding and directing a nongovernmental organisation (NGO) working with grassroots groups on HIV and human rights in Asia; serving as senior advisor on human rights at the Global Fund from 2013 to 2015 and consulting for HIV-related NGOs, as well as for the Board of the Global Fund. Among these projects is a study conducted for a consortium of civil society networks in Sub-Saharan Africa on the experiences of key populations in engaging with global health financing consultations. The study combined an online survey, fieldwork and follow-up interviews.

The following section discusses key population size estimates, and their importance in measuring progress towards the SDG target on HIV. I argue that pressure is increasing on countries to produce data about HIV-related key populations, including size estimates, both to report against the SDG, and perhaps more urgently, to meet pressure from global health financing mechanisms that finance national HIV programmes. Those health financing mechanisms are in turn under pressure from their own donors – bilateral aid agencies suffering from ‘AIDS fatigue’, who face competing demands for limited funds. As part of their efforts to gather this more granular data about key populations from countries, global health financing mechanisms have opened up more space for consultation and engagement by key populations representatives at the country level. Groups that represent key populations are as a result shifting their roles, and claiming more public space in order to critique the politics that shape data produced about them, and demand a greater say over the process of producing data and monitoring progress towards the ‘end of AIDS’.
About key population size estimates

SDG target 3.3 specifically addresses HIV: ‘By 2030, end the epidemics of AIDS, tuberculosis, malaria and neglected tropical diseases and combat hepatitis, water-borne diseases and other communicable diseases.’ The United Nations has an existing infrastructure for monitoring more specific progress towards the end of AIDS: a system of national reporting to UNAIDS. Following on the approval of the SDGs, the UN General Assembly held the above-mentioned High-Level Meeting on ending AIDS in 2016, at which they approved a UNAIDS 2016–21 Strategy and ten ‘Fast-Track Commitments’. These commitments, generated by UNAIDS based on consultation with countries and experts, breaks down the broad ‘end of AIDS’ target from SDG 3.3 into a series of more measurable targets, intended to spur faster global progress with interventions and in specific populations.

Two of the ten Fast-Track Commitments are directly relevant to this article. First, the widely-known ‘90-90-90 targets’ commit to ensure that ‘Ninety percent of people living with HIV are tested, ninety percent of those tested are on antiretroviral treatment (ART), and ninety percent of those tested are virally suppressed’. Another target commits to ‘Ensuring that 90% of people at risk of HIV infection have access to comprehensive HIV prevention services, including sex workers and their clients, men who have sex with men, people who inject drugs and prisoners’.

Both the 90-90-90 target and the target for prevention services are health service coverage indicators, meaning they measure the percentages of specific populations who are ‘covered’ by a health service such as prevention or treatment. The named population provides a denominator for these coverage indicators: for example, the number of people living with HIV, sex workers and their clients, men who have sex with men, and people who inject drugs in each country. Governments report biannually to UNAIDS on both the key population size estimates and the indicators, based on data gathered from health facilities in their countries. They use the Global AIDS Response Progress Reports (GARPR) for reporting, a system which uses a combination of narrative reporting and quantitative tools. UNAIDS posts the resulting quantitative numbers online, ensuring transparency and accountability for country-reported data. Thus, reporting for the SDG on AIDS, while produced by countries, is coordinated by UNAIDS through its national, regional and Geneva offices.

In addition to enabling countries to report to UNAIDS on their progress towards the ‘end of AIDS’, key population size estimates have other uses. They enable epidemiologists to know the numbers of people whose behaviours put them at increased risk of HIV, and thus to ‘estimate the future of the epidemic’; to ‘convince policy makers and funders of the existence and magnitude’ of the epidemic and to plan and implement specific and targeted prevention, care and treatment programmes that can reach those populations. Size estimates are also used as a basis and justification for resource allocation, determining which health services are funded, and which specific vulnerable populations are served in order to accelerate measurable progress.

WHO and UNAIDS recommend beginning a population size estimate by defining the population and geographic area; conducting formative research using qualitative research methods to learn more about visibility and practices of the population to be studied; and reviewing available data. Research methods for the size estimation include census and
enumeration methods (for example, using face-to-face interviews to count populations), the capture-recapture method (in which successive groups of people are counted in a given location), ‘snowball’ sampling (in which respondents introduce other respondents) and others.25 Because of the challenges in measuring hidden populations, many key population size estimates use several methods and triangulate the results.

However, progress in producing size estimates is slow: a 2015 study of 140 countries found that fewer than 100 had size estimates for even one key population group, and even these reported size estimates had numerous gaps and omissions.26 Stigma, discrimination, homophobia and criminalisation all make accurate counts difficult to produce. Said Barbra Wangare in Kenya, about the transgender population there:

Femininity is frowned upon in Africa. You’re not able to transition, you’re not even able to self-identify… Because of the spaces I occupy … the closest identity I can work with is as a gay man, so I go to the clinic as a gay man, and my numbers go away.27

Despite the challenges in counting hidden populations, Wangare continues to push for Kenya to produce a key population size estimate for transgender people. Speaking of her participation in national HIV consultations for the Global Fund and PEPFAR in Kenya, Wangare said:

I go to these meetings and ask, ‘Where are the interventions for trans people?’ They say, ‘We don’t have the data, there’s nothing we can do.’ I say, ‘If you want data, the only way is to look for the numbers. You’re not putting in the effort.’ There has never been a size estimate for trans in Kenya.28

Wangare’s experience of pushing for programmes to serve transgender people and being told that there is no evidence to justify these programmes exemplifies a larger tension that exists in HIV: between the hidden nature of key populations, who like the organisations described at the beginning of this article, often choose invisibility to avoid stigma, arrest and violence, and the need to quantify and make those populations visible in order to justify financing of urgently-needed medical services. This tension Wangare describes between visibility and invisibility, short-term security and long-term health, plays out at the national level in health resourcing for Kenya’s HIV response.

As she notes, this tension also plays out in a larger political tug-of-war underway between global health financing mechanisms, who urgently want data on key populations; national health programmes, which may be less committed to obtaining that data; and community activists, who both want the data and are sensitive to the risks. Quantitative evidence about hidden key populations sit at the nexus of the power struggle. The following section explores these tensions in the context of political economic forces at the global level.

Global health aid and the push for data

While the SDGs have increased the demand for key population size estimates, the pressure on global health agencies to demonstrate their impact to increasingly reluctant bilateral donors, who directly finance global HIV programmes as well as their own bilateral HIV programmes in developing countries, has made granular HIV data an urgent imperative. As discussed below, ambitious global health goals and a shrinking pool of global health aid are increasing demand for evidence of impact by health financing agencies – who fear that ‘donor AIDS fatigue’ will turn into permanent exhaustion and lack of funding.29
The new Sustainable Development Goals (SDGs) significantly raise the expectations of what can be achieved. As mentioned above, SDG 3.3 commits to ‘end[ing] the epidemics of AIDS, tuberculosis, malaria and neglected tropical diseases’ (emphasis added). This goal of ‘ending AIDS’ represents a significant increase in ambition from the Millennium Development Goals (MDGs), which had the slightly less ambitious goal of ‘halting and reversing the spread’ of HIV, tuberculosis and malaria, not permanently ‘ending’ it.30

Ending HIV in even one country is currently a remote goal. Even few developed countries have approached it, let alone lower-income countries where the HIV burden is highest.31 Among AIDS activists, there is scepticism that a global ‘end of AIDS’ is achievable so quickly, given the challenges in particular with reaching key populations in contexts of growing social and economic inequality. In the words of South African AIDS activist Mark Heywood:

In activist meetings a very different picture is emerging to the optimistic one that government officials, ours included, wanted to make the AIDS story. There are medicine stock-outs in many countries. Sex workers and drugs users are humiliated, imprisoned and sometimes murdered. Poor people in rich countries are being left behind by the artificial segmentation dreamed up by some bright spark in the World Bank that declares certain developing countries ‘middle income’, ignoring the local context of inequality, corruption and severe deprivation.32

Similarly, AIDS activist Julian Hows, reporting to the International AIDS Conference in Durban from the Positive Leadership Summit pre-conference, quipped that without more funding to reach key populations, ‘90-90-90 is all fur coat and no knickers’.33 However, the bilateral government donors to WHO, UNAIDS and the Global Fund (such as the US, UK, European Union, Japan and France) suffer from AIDS fatigue, and if the world succeeded in ‘ending AIDS’ with a massive last push, that would release significant amounts of aid for other purposes – for instance, the global refugee crisis, or climate change.

The amount required to achieve this ambitious goal far exceeds what bilateral donors have currently committed. UNAIDS has called for a $26.2 billion investment in lower- and middle-income countries by 2020 to meet SDG 3.3 in just those countries.34 However, global spending on HIV declined in 2015 from the previous year’s high of $8.6 billion to $7.5 billion.35 Similarly, for tuberculosis, a leading cause of death for people living with HIV, the world saw significant aid cutbacks in 2016, a gap expected to increase.36 Global funding for tuberculosis research and development dropped by $53.4 million in 2015.37

In her opening remarks to WHO’s 2016 financing dialogue, Director-General Margaret Chan decried ‘serious funding shortfalls’ to donors: ‘You have asked us to do more, especially through the health emergencies programme. [But] in the case of core voluntary contributions, income has decreased.’38 UNAIDS has argued that lower-middle income countries could pay more towards the AIDS response, a proposal civil society groups call ‘magical thinking’.39

Growing donor fatigue has ratcheted up the pressure on global health agencies to demonstrate results in order to justify continued funding. This pressure is passed down from global health agencies to national programmes, who must produce the data. Thus, the two leading global health financing agencies for HIV – the Global Fund, and
PEPFAR – have since 2014 called for better HIV data to better target investments on specific locations and specific populations. To spur its own progress, in 2011 to 1016, the Global Fund set a corporate Key Performance Indicator to monitor the number of countries that develop key population size estimates.

In their efforts to persuade countries to gather data on key populations, the Global Fund and PEPFAR have pointed to scientific research suggesting that a targeted approach to siting HIV programmes in key population ‘hot spots’ has greater impact than a more uniform approach:

A uniform strategy, which does not use available intelligence on the epidemic, will fail to be as effective as a strategy that does. By use of a public health approach that focuses resources based on an epidemiological understanding of subnational geographical areas and key affected populations, and selects the package of interventions most likely to have an effect according to the drivers of each HIV stronghold, the efficiency and effectiveness of programming could be greatly increased.

This is logical, but what are the risks of gathering such specific information about the number and locations of criminalised and hidden key populations? As UNAIDS notes, mapping that highlights ‘hot spots’ where key populations congregate could draw attention of law enforcement, leading to police raids and abuse. The Global Network of Sex Work Projects, which represents sex workers, also underscore risks in geospatial mapping of sex workers, including ‘loss of housing and involvement of social services if the worker has children or other dependents … loss of income … [and] breaches of confidentiality about identification, health status, being a sex worker’. In a policy brief, NSWP describes an instance where a university-led population size estimate in Kenya led to police raids, arrests and sensationalistic media coverage. As James C. Scott notes in another context, benevolent state projects of mapping can make a hidden population visible in ways that do real harm. Financial aid given to fulfil the extraterritorial obligations of developed countries has exerted political pressure to produce data that justifies this aid, but health data is not produced in a politics-free zone. Power is inherent in a process in which one group studies another, especially when that information is used in governance. A growing body of anthropological and human rights literature has problematised the use of indicators and related data, like key population size estimates, in global governance.

**Critiques of indicators in global governance**

The use of indicators in global governance is on the rise, exemplified by the growing demand for quantitative data to report on the SDGs. However, anthropologists and human rights scholars have raised concerns about the ways this trend alienates global health governance from public participation. Global development aid, including health aid, is allocated, spent and evaluated at a pace never before seen, in ways that create challenges for risk assessment and management. Numerical indicators, such as the SDGs, offer efficiency and speed of decision-making about this aid, two features that are attractive to international aid agencies which must make difficult decisions about aid allocations and explain them persuasively to diverse stakeholders. However, ‘the production of indicators is itself a political process, shaped by the power to categorize, count, analyze, and promote a system of knowledge that has effects beyond the producers’.
These political decisions include the summarising and measurement of abstract values, such as ‘good governance’; and the reduction of complex phenomena to less ambiguous values based on complex bodies of data. Indicators, whose interpretive work is often ‘invisible’, mask the political values implicit in the conceptualisation and collection of data. They generate arbitrary measurements of value-laden concepts which may be subject to multiple competing interpretations. Because indicators represent abstractions of diverse settings, such as countries, they may miss internal inequalities.

Numerical indicators used in global governance can also create a false sense of transparency. Because of their reliance on data produced through a variety of quantitative methodologies, indicators are often based on information comprehensible to a small group of experts, but that are largely incomprehensible to government officials, media or the public. The development and upkeep of indices has become a minor technocratic industry. Often, the work of producing global governance indicators and gathering data to report against them is led by consulting firms and academic institutes working for financial benefits or prestige.

In the context of global health, medical anthropologists have raised questions about the pressures on health programmes that can be created by donor-driven targets and the related demand for quantitative research data. Vincanne Adams and colleagues argue that the pressure to produce data to meet indicators set by global health agencies actually discourage health programmes in rural regions from tailoring their approaches to local contexts where national numbers ‘do not reflect reality on the ground’. In Malawi, Claire L. Wendland finds that the efforts by national leaders to promote their success in reducing maternal mortality rates, a target set by global governance agencies, may have led to data manipulation in order to minimise actual deaths. Because of the values associated with positive performance on indicators of global governance, indicators may produce perverse incentives to report positively by states.

For these and other reasons, some medical anthropologists such as Adams have pressed for more use of deep ethnography in analysing health programme performance, rather than quantitative evidence of the type produced by Randomized Controlled Trials (RCTs). It is difficult to see how slow research would fit into the quantitative systems in which countries report on global HIV targets, in turn linked to SDG 3.3. Despite the issue above, quantitative measurement and reporting are deeply entrenched in national health programmes, and are integral to the fast-paced process of awarding and evaluating global health aid.

At the same time, as discussed below, the Global Fund and PEPFAR have recognised that this quantitative data does not always capture the complex realities of treatment access for hidden key populations, and have also expanded stakeholder consultations in countries that receive HIV aid. In response, key populations have begun to seize this political space to challenge data produced about them by national programmes. In some cases, they have begun to demand a right to validate both the data and the methods used to produce it.

**Key populations and global health aid**

Prior to 2013, the Global Fund distributed funding to national HIV programmes through rounds-based applications. In 2013, this changed with the launch of the ‘new funding...
model’ (now no longer new, and just ‘the funding model’). At the beginning of each three-year funding cycle, countries are notified of their allocations. National committees (known as Country Coordinating Mechanisms, or CCMs) consult with diverse stakeholders, review the epidemiological data and past performance of their grants, and submit a written request for funding. A critical change in the process was the ‘country dialogue’ which required CCMs to demonstrate that they had consulted with representatives of women, key populations and people living with the three diseases, among others.

In 2014, PEPFAR similarly began to include key population consultations in their processes. PEPFAR develops annual Country Operational Plans (COPs) with programmatic descriptions, budgetary information and description of the planned uses of all sources of US government HIV/AIDS funding for the fiscal year. Like Global Fund CCMs, PEPFAR country teams are required to report to headquarters in writing on their process of consultation with civil society, including key populations representatives.

In addition, the Global Fund invested $15 million in a technical assistance programme to strengthen key populations engagement in its consultation processes. PEPFAR and USAID launched LINKAGES, a programme that funds HIV prevention and care work among key populations, as well as supporting key populations to ‘mobilize and advocate for changes in laws and the conduct of police, healthcare workers and policymakers’. In 2016, PEPFAR also announced a Key Populations Investment Fund.

For both agencies, which work closely with UNAIDS country offices to conduct the consultations, the increased support for key populations advocacy and consultation takes place in parallel with pressure on national governments to produce improved data on HIV among key populations. Both aid agencies are also investing in strengthening data systems which are used to report to the agencies, to UNAIDS, and through UNAIDS for SDG 3.3.

Progress in developing inclusive consultations has not been without challenges. The Global Fund Office of the Inspector General found that CCMs are often failing to comply with new, more inclusive standards of representation; and civil society groups have raised concerns that their consultation is not always meaningful. The increased consultation has also created new contests between increasingly vocal key populations and their national HIV programmes over the quality of data produced about them.

‘You’re not putting in the effort’: key populations question the data

A critical right in relation to governance of HIV programming is the right to participation. From the outset, the AIDS response was driven by activists. Jennifer Chan notes that self-taught activists mastered the intricacies of ‘biomedicine, law, economics, and politics as the epidemic unfolded at an alarming speed’, as well as ‘global AIDS governance: who is in charge and how priorities are set.’ In 2007, UNAIDS articulated this engagement as a principle linked to human rights principles, the Greater Involvement of People living with HIV (GIPA):

GIPA is not a project or a programme. It is a principle that aims to realize the rights and responsibilities of people living with HIV, including their right to self-determination and participation in decision-making processes that affect their lives.
Today, that right to participation is also being taken up by key populations activists, who increasingly assert a right to audit the work of power-holders. An example of this is the above-mentioned study in 2016 on the experiences of key populations in engaging with global health financing consultations. The consortium that sponsored the study included African Men for Sexual Health and Rights (AMSHeR), a coalition of 18 organisations led by men who have sex with men and LGBT people across sub-Saharan Africa; Africa Sex Workers Alliance (ASWA), a movement/network of sex workers, women’s organisations and NGOs serving sex workers; and two organisations representing transgender African people, Gender DynamiX and Transbantu Zambia Association. A number of respondents raised concerns about the poor quality of health data in their consultations, which several said they believed was motivated by government desire to minimise or deny the size of their populations.

This was especially a concern for transgender people. UNAIDS estimates a global HIV prevalence rate among transgender people of 19%; in other words, approximately one in five transgender people is living with HIV. This exceptionally high prevalence would suggest a serious health crisis that merits urgent action. However, while all UN member states agree to report on HIV data, as of 2016, only 20 out of 193 UN member states had ever reported any data at all on HIV among transgender people to UNAIDS. None of these 20 countries is in Sub-Saharan Africa.

As a result, African transgender communities are clear victims of the data paradox mentioned above. Like Barbra Wangare in Kenya, transgender activists pressing for Global Fund and PEPFAR funding to include programmes often report being told in health financing consultations there was no evidence of the existence of transgender people or their HIV prevalence. The problem is even more profound for transgender men, who are perhaps even more invisible than trans women, if that is possible. In Uganda, one interviewee said,

We have always asked for support to do research and come up with data, but all in vain, and yet I as a trans man know there’s HIV among the trans men. People rarely believe in trans men. We have been left out of a lot of projects and activities. (emphasis added)

Note that the interviewee describes people ‘not believing in trans men’, as if they were leprechauns, or angels – a phenomenon whose existential reality others could debate, even while the physical person stood before them, demanding health care. Key populations often hide for safety reasons, and the fact of this enforced invisibility renders their corporal existence, and corporal needs, a matter of debate for others. Key population size estimates are controversial because they provide quantitative evidence of the bodies that mainstream society may otherwise refuse to believe exist, and who might otherwise die.

Similarly, few countries report on HIV, including population size estimates, for people who inject drugs. Here again the data paradox is especially glaring in Africa: according to UNAIDS, only 15 out of 55 African states has a current size estimate for people who inject drugs. Many of the reported size estimates probably underestimate the actual populations: for instance, Niger, which reported a drug user population of 670 as of 2013; and Guinea-Bissau, an emerging hub for drug trafficking, which has no size estimate at all for people who inject drugs. Nigerian and Ugandan interviewees I spoke with for the African key populations report described failed attempts to get their countries to request funding for
harm reduction services for people who inject drugs in their Global Fund and PEPFAR financing; again, resisted because neither country had a size estimate for people who inject drugs.\textsuperscript{75}

The questions raised by key populations in health financing consultations about the data have led some countries to commit to conducting new population size estimates, but this in turn sometimes creates new issues and new debates. In Kenya, Peter Njame of ISHTAR-MSM said that Kenya presented research in PEPFAR COP consultations stating that there were 10,000 MSM in Kenya (citation). Njane flatly disputed the size estimate:

We had disputes over how the data was collected. We questioned where they got their information. Donors were there, we’re shown the final product, the money has been used, and the community didn’t accept it.\textsuperscript{76}

After Njane and others put their feet down, the Kenyan health authorities made plans to conduct a new size estimate for key populations, funded by the Global Fund and PEPFAR. Kenya’s health ministry has mandated the use of biometrics (such as fingerprinting, toe-printing and iris recognition) to track individuals who test for HIV. They proposed to expand the practice for the key populations size estimate, in order to avoid overcounting of key populations.

Kenyan key populations groups and representatives of people living with HIV responded with outrage.\textsuperscript{77} Maureen Milanga, a Kenyan human rights lawyer and Alternate Board Member of the Communities Delegation to the Global Fund Board, wrote:

\begin{quote}
[W]e are deeply concerned that the government of Kenya is pushing to use “biometrics” as part of its Global Fund- and PEPFAR-supported key population (KP) size estimation study … Doing so will undermine human rights and the accuracy of the very data the study is seeking to compile. The Kenya Key Population Consortium, comprising networks of organizations representing men having sex with men, sex workers and people who use drugs – totaling over 90 key population led organizations and allies – have requested an emergency call with government, donors and partners to discuss the study, which will be carried out by the Ministry of Health.\textsuperscript{78}
\end{quote}

She notes that the key populations consortium

has fought for Kenya to update its key populations size estimates, which have been unacceptably conservative. Artificially low key populations estimates result in unambitious target setting in the response to HIV services and leaves too many behind.\textsuperscript{79}

This kind of assertive questioning of the data and methodologies by key populations troubles the traditional subject-object relationship in public health research. Normally, epidemiologists count and key populations are counted. As Paulo Longo, a former sex worker and co-founder of the Global Network of Sex Work Projects (NSWP) writes:

Sex workers are used to being ‘subjects’ of research and generally not participating in the process. Their role is usually restricted to giving information and facilitating access to (other) respondents. They generally do not have easy access to the results and these are not commonly applied for their benefit.\textsuperscript{80}

What is more, this subjectivity comes with other costs. Bringing the bodies of invisibilised key populations into the public eye creates risks for those made visible – the risk of stigma and discrimination, the risk of arrest in many countries, even the risk of violence; and the
pressure on countries to produce data on key populations also brings the risk of forced testing and treatment. There have been numerous cases in which data was gathered about key populations forcibly, without informed consent or basic privacy protections, sometimes even resulting in publication of identifying data, including names and photographs. Key populations advocates have opposed forced testing for some time; NSWP has called mandatory HIV or STI testing ‘violent measures that breach the right to be free from degrading treatment and the rights to bodily integrity and privacy’, arguing that the practice discourages ‘sex workers from accessing health and social services for fear of having their identity exposed’. All of the global key populations networks have raised concerns about privacy protection in the process of health research. But the engagement by Kenyan key populations in debates over choice of methodology is a newer development. In 2016, NSWP produced a brief for its members on programmatic mapping as a method of size estimation, titled, Mapping and Population Size Estimates of Sex Workers: Proceed with Caution, which warns that the data used in conducting population size estimates ‘can potentially allow for the continued tracking of sex workers by health authorities, law enforcement agencies or anti-sex work groups’. NSWP’s recommendations include strict measures to ensure data is protected, including specific measures in use of Unique Identifier Codes, management of information in data sets, and that ‘Sex workers must fully understand and have control and input over the process of data collection, analysis, and dissemination of the information’, among other measures. It is not uncommon for epidemiologists conducting key population size estimates to include key populations in population size estimation projects, but usually only as low-paid data-gatherers or ‘enumerators’. In a few countries, key populations-led organisations have worked in something approaching a more equal partnership with epidemiologists on the research and publication of key population size estimates. In Malawi, the Centre for the Development of People (CEDEP) partnered with scholars from the Johns Hopkins Bloomberg School of Public Health and the University of Malawi to conduct ‘the first prevalence estimate of men who have sex with men in the country’. In 2017, a regional human rights organisation, Caribbean Vulnerable Communities (CVC) is partnering with epidemiologists from the University of Alabama at Birmingham and local key population groups to conduct size estimates in small island countries in the Eastern Caribbean, where small populations can make protecting privacy especially challenging. This more consultative approach to key population size estimation is now recommended by technical guidance on HIV and sexually transmitted infection (STI) programmes jointly developed by UN agencies, USAID, PEPFAR and the Global Forum on MSM and HIV. It suggests a new power dynamic may be developed, in which key populations are not only the objects of research, but active agents in gathering, validating and analysing the data. The SDGs, and the economic pressures from donors to produce more and better data, are creating new spaces for ground-up engagement by key populations in quantitative measurement. Representatives of sex worker-led organisations go one step further in asserting that research processes be not just developed in partnership with, but actually ‘sex worker-led and informed by sex workers’ realities’. Ivan Wolffers argues that much research about sex work produces confirmation bias, resulting in research removed from the realities of sex workers’ lives. Instead, he argues for ‘participatory community-based
approaches ... based on a dialogue between sex workers’ experiences and needs, and researchers’ scientific skills.90 As an example of this approach, Paulo Longo, a former sex worker, describes a Brazilian HIV study in which Longo was also a Principal Investigator. Sex workers ‘actively participat[ed] in all phases, from the design of the research to the production and distribution of the reports’.91 Responding to the steady flow of demands for aid in research on sex workers, a number of sex-worker-led organisations have published guidelines for researchers that insist on the right of sex workers to define the relationship and parameters of the research.92

In other words, groups that were in the past the objects of quantitative research are beginning to reposition themselves as critical subjects and as Principal Investigators. While this trend is incipient, it suggests more consultative possibilities for the future development of not only health data, but of the indicators and targets themselves. If key populations have the right to play a leading role in research, should that right not extend to participating in the process of defining the actual indicators?

**Conclusion**

This article has explored some of the real-world power dynamics that will shape data-gathering related to the SDG on health. The progressive realisation of the right to health, and the fulfilment of the ambitious SDG 3.3 on health, depends in part on identifying and reaching the marginalised populations most vulnerable to HIV, and on gathering quantitative data to show that a significant percentage of these populations have been ‘covered’ with essential HIV services. At the same time, funding shortfalls have increased pressure on global health aid created by diminishing donor goodwill has created pressure on HIV programmes to demonstrate impact, pushing them to gather increasingly granular and precise data about key populations. The absence of health data on key populations has real resource implications: it means that health resources will be allocated elsewhere, and that programmes to serve the specific needs of these groups will be neither planned nor funded. In the longer term, lack of impact data may affect the ability of health aid agencies to persuade bilateral donors to continue their investments.

In contexts of criminalisation, key populations often choose to remain invisible in order to survive. This creates a data paradox, in which invisibility reinforces lack of resources and services. However, country-level consultations by national health programmes and international donors with key populations have created openings for some marginalised communities to come forward to challenge the validity of both the data produced about them, and the intrusive methods used to produce it. In some cases, key populations advocates are interrogating the political aims behind the data, and demanding a right to participate and a voice in the process of defining and conducting the research that produces it.

As noted above, anthropologists and human rights scholars have challenged the epistemology of indicators used in global health governance, and questioned the quantitative research methods used to produce data to report against them. As a solution to the problems posed by over-reliance on quantitative data in global health governance, Adams, Burke and Whitemarsh have called for a shift away from quantitative research towards ‘slow research’: context-specific ethnography that can produce more nuanced textual analyses of locally-specific programmes.93 However, deep ethnographic research is no freer of the underlying power imbalances involved in representation than are RCTs, and just as
capable of oversimplifying and misrepresenting complex realities. The distance between signifier and signified has been charted by semioticians and deconstructionists.\textsuperscript{94} No form of representation, whether narrative text or numbers, can fully capture the complexity, diversity and multifaceted nature of lived individual experiences.

Numerical indicators used in global governance are a relatively new system of signs, a language of synecdoches that is rapidly evolving. These signs are far from immutable or fixed. New methodologies can shift the power dynamics and complicate the relationships between researcher and researched.

Rather than retreating from the problem posed by quantitative measurement into a more familiar world of qualitative research and narrative representation, some community-based organisations have begun to deconstruct and engage with quantitative methods, proposing alternative processes that shift the power balance between subject and object. Indicators are designed to shine a light on areas where some actors feel that progress is needed. In the hands of advocates, they can also be advocacy tools used to press for change.

Notes

1. Based on review of the scientific evidence and consultation with experts, including key populations representatives themselves, WHO has defined key populations as: ‘Defined groups who, due to specific higher-risk behaviors, are at increased risk of HIV irrespective of the epidemic type or local context. Also, they often have legal and social issues related to their behaviors that increase their vulnerability to HIV. These guidelines focus on five key populations: 1) men who have sex with men, 2) people who inject drugs, 3) people in prisons and other closed settings, 4) sex workers and 5) transgender people. People in prisons and other closed settings are included in these guidelines also because of the often high levels of incarceration of the other groups and the increased risk behaviours and lack of HIV services in these settings (WHO). In addition, WHO notes there are ‘vulnerable populations’ who are ‘particularly vulnerable to HIV infection in certain situations or contexts, such as adolescents (particularly adolescent girls in sub-Saharan Africa), orphans, street children, people with disabilities and migrant and mobile workers’. This article focuses on issues pertaining to key population size estimates and related HIV data gathered for the purposes of targeting programmatic interventions and measuring progress on the HIV response for men who have sex with men, sex workers, transgender people and people who inject drugs. All of these groups may be represented among prisoners; who are moreover a population that should be served by health services within prisons. For that reason, population size estimates are not normally done for prisoners.


51. Davis, Kingsbury and Merry, ‘Indicators as Tools’.

52. Satterthwaite and Rosga, ‘Trust in Indicators’; Davis and Kruse, ‘Taking the Measure of Law’.

53. Winkler, Satterthwaite and de Albuquerque, ‘Measuring What We Treasure’.

54. Davis, Kingsbury and Merry, *The Quiet Power of Indicators*.


60. Adams, ‘Slow Research’.


69. Esom et al., African Key Populations.

70. Esom et al., African Key Populations, 9.


73. Ibid.


75. Esom et al., African Key Populations, 18.

76. Ibid.


78. Milanga, ‘Fighting to Protect Human Rights’.

79. Ibid.


84. NSWP, Mapping and Population Size Estimates of Sex Workers, 7.


86. A. L. Wirtz, G. Trapence, V. B. Gama et al., HIV Prevalence and Socio-Behavioral Characteristics Among Men Who Have Sex With Men across Seven Sites in Malawi, Final report to the UN Joint Team on HIV and AIDS in Malawi (Lilongwe: Johns Hopkins University and the Center for the Development of People, 2014).

87. John Waters, personal communication with the author, August 4, 2016.


93. Adams, Burke and Whitmarsh, ‘Slow Research’.


**Disclosure statement**

I am reporting that at the time of writing this article I was a consultant to the chair and co-chair of the Implementers Group on the Board of the Global Fund to Fight AIDS, TB and Malaria. I have disclosed those interests fully.

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