WHO-EM/STD/156/E

Report on the

Regional meeting of experts on surveillance and strategic information

Cairo, Egypt 24–26 June 2013



Report on the

Regional meeting of experts on surveillance and strategic information

Cairo, Egypt 24–26 June 2013



© World Health Organization 2014

All rights reserved.

The designations employed and the presentation of the material in this publication do not imply the expression of any opinion whatsoever on the part of the World Health Organization concerning the legal status of any country, territory, city or area or of its authorities, or concerning the delimitation of its frontiers or boundaries. Dotted lines on maps represent approximate border lines for which there may not yet be full agreement.

The mention of specific companies or of certain manufacturers' products does not imply that they are endorsed or recommended by the World Health Organization in preference to others of a similar nature that are not mentioned. Errors and omissions excepted, the names of proprietary products are distinguished by initial capital letters.

All reasonable precautions have been taken by the World Health Organization to verify the information contained in this publication. However, the published material is being distributed without warranty of any kind, either expressed or implied. The responsibility for the interpretation and use of the material lies with the reader. In no event shall the World Health Organization be liable for damages arising from its use.

Publications of the World Health Organization can be obtained from Knowledge Sharing and Production, World Health Organization, Regional Office for the Eastern Mediterranean, PO Box 7608, Nasr City, Cairo 11371, Egypt (tel: +202 2670 2535, fax: +202 2670 2492; email: emrgoksp@who.int). Requests for permission to reproduce, in part or in whole, or to translate publications of WHO Regional Office for the Eastern Mediterranean – whether for sale or for noncommercial distribution – should be addressed to WHO Regional Office for the Eastern Mediterranean, at the above address: email: emrgogap@who.int.

CONTENTS

1.	INT	RODUCTION	I			
2.	ΔC^{r}	ΓΙVITIES OF THE REGIONAL EXPERT GROUP SINCE THE LAST MEI	FTINGO			
۷.	2.1	STI journal supplement				
	2.1	Defining key populations at higher risk				
	2.2	Defining key populations at nigher risk				
3.	POF	POPULATION SIZE ESTIMATION: METHODOLOGIES AND THEIR				
		PLICATION IN THE REGION	5			
	3.1	Regional overview				
	3.2	Sudan size estimate				
	3.3	Tunisia size estimate				
	3.4	Mapping in South Sudan				
	3.5	Lessons learnt from sub-Saharan Africa about size estimation of key popul				
	0.0	at higher risk				
	3.6	Discussion				
	3.7	Network scale-up in the Islamic Republic of Iran				
	3.8	Population size estimation tool				
	3.9	Discussion on priorities for size estimation				
4.	$C\Lambda$	SE REPORTING	13			
4.	4.1	Overview of case reporting				
	4.1	Using case reporting for HIV estimates				
	4.2	Case notification				
	4.3	Discussion on priorities for case reporting				
	4.4	Discussion on priorities for case reporting	10			
5.	HIV	ESTIMATIONS IN THE REGION	18			
	5.1	Using SPECTRUM for estimates	18			
	5.2	Discussion: priorities for improving HIV estimates				
6.	ACT	TION POINTS	23			
	Ann	nexes				
1.		OGRAMME	26			
2		T OE DA DTICIDA NTC				

WHO-EM/STD/156/E

1. INTRODUCTION

A meeting of the regional expert reference group on surveillance and strategic information for the Eastern Mediterranean Region of WHO and the Middle East and North Africa Region of UNAIDS¹ was held in Cairo on June 24–26, 2013. This was the second meeting of the reference group. The first took place in May 2011. Participants of the meeting included epidemiologists, social scientists and public health experts representing WHO, UNAIDS, the United States Centers for Disease Control and Prevention (CDC), the Kerman Regional Knowledge Hub, the WHO collaborating centre for HIV surveillance in Zagreb, the Weill Cornell Medical College, and several other organizations involved with surveillance activities in the region.

The meeting began with a welcome by Dr Jaouad Mahjour, Director, Communicable Disease Control, WHO Regional Office for the Eastern Mediterranean, who expressed the support of the WHO Regional Director for the Eastern Mediterranean for the expert reference group, and his own hopes that the meeting would contribute to improved data and information to guide programmes in the region, which had been hampered by limited capacity and stigma related to HIV.

Ali Feizzadeh, Regional Strategic Information Advisor for UNAIDS Regional Support Team, made remarks on behalf of the regional support team director, in which he focused on the progress that had been made in the past few years in generating strategic information, despite the fact that there was still a long way to go. There were now many examples of size estimates and surveys in the region, where before there were very few, so things were moving in the right direction.

Gabriele Riedner, Regional Adviser, HIV/AIDS and Sexually Transmitted Diseases, WHO Regional Office for the Eastern Mediterranean, laid out the objectives of the meeting which would focus on three important themes:

- Size estimates of most-at-risk populations
- HIV case reporting
- Estimates of people living with HIV/AIDS (PLHIV).

She explained that for each topic there would be an update on the current situation and the challenges, followed by presentations describing relevant activities in the region, followed by a discussion of the role of the regional experts group in supporting those activities going forward.

The meeting programme and list of participants are attached as Annexes 1 and 2, respectively.

¹ The WHO Eastern Mediterranean Region and UNAIDS Middle East and North Africa Region are collectively referred to as "the region" for the remainder of this report.

2. ACTIVITIES OF THE REGIONAL EXPERT GROUP SINCE THE LAST MEETING

Before starting on the thematic areas, Laith Abu-Raddad provided an update on two main activities undertaken by the reference group during the two-year period since the last meeting: 1) the supplement to the Journal of Sexually Transmitted Infections; and 2) efforts to establish standardized definitions for key populations at higher risk that would be appropriate for HIV surveillance purposes in the region.

2.1 STI journal supplement

One of the issues identified by the reference group in 2011 was the need for more scientific publications of the work being done in the region. To address this need, the decision was taken to sponsor a supplement issue of one of the major journals. The Journal of Sexually Transmitted Infections was chosen because of the relevance of its subject matter, high readership, easy access, and potential for impact.

A seven-member regional editorial board was formed and two associate editors were appointed, Laith Abu Raddad (representing the editorial board), and Khalil Ghanem, representing the journal.

The process of completing the supplement has been lengthy with many challenges including ensuring a high standard and quality of content, keeping the topics interesting and unique, and producing/translating high quality manuscripts in English. At the time of the meeting, out of a total of 13 articles planned for the supplement, 5 had been accepted, 4 were under revision, 2 were under review, and 2 were not yet submitted.

A number of challenges were discussed in detail. One was the profile of people who are in a position to author papers because of their involvement in surveillance activities, and/or access to data (e.g. ministry or nongovernmental organization counterparts), but who lack the technical capacity and/or scientific background to produce the kind of publishable materials that meet journal standards. Partnering with national or international academic institutions was proposed as one partial solution to this problem. WHO and UNAIDS are not in a position to impose such collaboration. They can help by encouraging it or facilitating informal introductions. But ultimately, it is the ministry that has to want to delegate tasks to academic institutions.

Another challenge was the level of scientific content required by journals, and the conflict that sometimes arises between the need to publish what is going on in the region and the need for high quality. The quality of surveillance research is sometimes not comparable to data produced by "high-quality" scientific studies. That makes them difficult to publish, and creates a built-in disincentive to write surveillance papers. Solutions proposed to address this issue included the possibility of streamlining the process of publishing in the Eastern Mediterranean Health Journal. It was also mentioned that the journal jHASE was created specifically to provide a forum for publishing surveillance data, in part to address the reality that surveillance methods and surveillance data are "messy" and therefore perceived as not

qualifying as "sound" research. However, jHASE is not indexed in PubMed, which is offputting to some authors.

An offshoot of this discussion was about data use and whether there is a way to add a condition or requirement about open access to data (e.g. by the funding agencies). But this is difficult area because ultimately surveillance is the purview of the government, and the priority is to produce actionable reports, rather than publishable research manuscripts.

2.2 Defining key populations at higher risk

The next topic addressed was the development of standardized definitions of key populations at higher risk for surveillance purposes in the region. This was one of several needs identified at the 2011 meeting, related to improving the quality and validity of data for key populations at higher risk (the others being specificity and time-frame of behaviours, denominator issues, continuous variables and key indicators). The need for standardized definitions stemmed from observations about inconsistencies across studies in the region, and the need to improve the quality and validity of the information derived from the surveys. The diverse ways in which female sex workers, injecting drug users, and men who have sex with men are defined for surveillance activities, even though they are "labelled" the same way across countries (i.e. as FSWs, IDUs and MSM) is perceived as a problem for characterizing epidemics in the region and comparing results across the region.

After the 2011 meeting, a small working group was dedicated to address this issue. The main questions they grappled with were "frequency" and "duration" of risk behaviour, and trying to define how often someone needs to engage in a behaviour, and within what time period, before they are considered to be at "high risk", because of repeated potential exposure to the virus.

Abu-Raddad reported that the definitions proposed by the group were the result of long discussions where many factors were considered. The group found it difficult to find standardized definitions that would be satisfactory for all purposes, and in the end they limited themselves to a definition that would work well for bio-behavioural surveys. The proposed definitions are:

- IDUs: Men and women who injected non-therapeutic drugs more than once in the last month
- MSM: Men who had anal sex (receptive or insertive) with men in the last six months
- Direct FSWs: Women who exchanged sex for money or goods in the last one month
- Indirect FSWs: Women who exchanged sex for money or goods in the last 12 months.

A more detailed description is attached at the back of this report

Several points were raised in the discussion that ensued:

- Abu-Raddad clarified that they used the long time-frame for indirect sex workers because of the seasonal nature of sex work for some women (e.g. during the tourist season).
- He also clarified that the distinction between direct and indirect sex workers relates to self-perception on the part of the women (i.e. whether the woman considers herself as a sex worker, whether sex work is her main source of income).
- One participant mentioned that it would be impossible for a woman to call herself a sex worker in his country (even if this was her regular activity).
- One participant thought that the distinction did not make sense, saying that some "indirect" sex workers (according to the proposed definition) might be more active, or have more partners, than some "direct" sex workers.
- One participant felt that there should be three divisions of sex workers (visible, not visible, and not acknowledged at all) to reflect the complexity of the situation in MENA countries.
- One participant thought the definition for IDUs would lead to under-estimation of HIV prevalence and risk behaviours, because it would not address the "core" drug users (who inject frequently).
- Another participant felt that the time period should be long for IDUs (up to one year) because some people move in and out of injecting and would be missed with the shorter timeframe.
- Several participants stressed their opinion that the populations should be defined in a
 way that captures "frequent risky behaviour", and that the behaviour is more important
 than the label. In particular there was a concern that defining sex workers as women
 who exchange sex for goods, casts a very wide net and potentially includes people with
 very low exposure.
- Another participant pointed out that when using network scale-up (as a method for
 measuring the size of key populations), it is not possible to get into the nuance of
 frequency of behaviour, so a simple definition is more appropriate (i.e. one that does not
 require respondents to know much detail about the behaviour of the persons in their
 network).
- Participants were divided on the question of the importance of standardized definitions that can enable cross-country comparisons (i.e. how important they are relative to other needs).
- The issue of how these definitions affect size estimations was also discussed (i.e.
 whether a broad definition will lead to a bigger size estimate than a more narrow
 definition).

In the end the group concluded that consensus on this issue is too difficult, even among experts. Keith Sabin mentioned that UNAIDS had tried to tackle the issue of standardized definitions for key populations at higher risk, but had to abandon the effort because it was too context specific. It seems that that countries need to make their own decisions based on their own context. Perhaps what is most important is to stress that definitions should be clear and well documented, so that they can be taken into account when the data are used. And even if there cannot be one common definition, it is still important and useful to map out the key populations at higher risk in the region.

At the end of Session 2 there was also a short update from Ali Haghdoost about efforts to standardize behavioural questions for key populations at higher risk. He reported that his team from the Kerman HIV Surveillance Knowledge Hub (HIVHub) had created a spreadsheet to look at the frequency of using different forms of questions and trying to explain why some forms are better than others and why. Haghdoost also mentioned the problem of bias (underreporting) of risky behaviour, and some efforts to calibrate underreporting by a PhD student who tried both complicated (Bayesian) and simpler methods.

There was a suggestion that perhaps a small group could be formed to provide guidance on calibrations and also what to take into consideration when coming up with definitions of key populations at higher risk, drawing on materials that are already available. But this was a general suggestion and there was no specific plan to follow-up.

3. POPULATION SIZE ESTIMATION: METHODOLOGIES AND THEIR APPLICATION IN THE REGION

3.1 Regional overview

This session began with an overview by Tobi Saidel of size estimation activities in the region in the past few years. In summary, the status in the region based mainly on the Surveillance Systems Regional Update (2012) is as follows:

- 12 countries reported to have conducted some size estimation activities in the recent past
- 7 countries used mapping, 7 used survey based multipliers, 1 did capture recapture (CRC), 1 did network scale-up (NSU) and 3 were unspecified
- 10 countries reported no size estimation activities
- Three countries reported to have national estimates

Fifteen countries are planning size estimation activities over the next few years, but many countries reported that they lack resources to address HIV issues in general. So it is not clear how much priority can or should be earmarked for stand-alone size estimation. (This was debated more in a later session).

Some general observations were shared with the group:

- Although most countries report that they do not have national size estimates, almost all
 countries develop "de facto" estimates for SPECTRUM models, which then have a
 tendency to "become" the national estimates.
- The values that are used for SPECTRUM across the region vary greatly
 - For MSM, some countries use a figure below 0.1% and other countries go as high as 2%.
 - Similarly for FSWs, the figures range from 0.1% up to nearly 1%
 - And for IDUs they range from 2% to 1.4%

The variation is related to how the groups are defined and the locations where size estimation data are available. In general, the countries using smaller proportions are including

the highest risk subset of the population, which is presumably the subset with the most exposure to HIV. The countries using the larger numbers are including a broader cross-section of the risk populations, which represent a mix of higher and lower risk subsets.

Countries which have conducted direct size estimation exercises involving mapping or survey based multipliers usually do them in a handful of geographic locations where there is a higher concentration of people engaging in high risk behaviours. These estimates help serve the purpose for local level planning, but are insufficient for deriving national level size estimates, which are required for strategic planning and modelling purposes, like SPECTRUM and Mode of Transmission (MOT).

Discussion

The group discussed the possibility of providing guidance to countries with respect to a range of reasonable or plausible size estimation values to use for activities requiring national size estimates in the region. The guidance would focus on the implications of using values at the high or low end of the range, given that those values represent a mix of population members with higher and lower levels of risk. Laith Abu Raddad mentioned that the MENA synthesis project might be helpful in providing the information (meta-analysis) for establishing what that range should be.

Keith Sabin also mentioned that UNAIDS Geneva has a new innovation which uses a mathematical approach to produce better estimates that account for clustering and hotspots, which might be helpful in countries with sparse size estimation data and clustering of risk.

Three presentations followed. One described Sudan's approach to using multiple size estimation methods to inform their national estimate. The second described Tunisia's efforts to develop national size estimates, and the third shared the experience of mapping in South Sudan.

3.2 Sudan size estimate

Mohammed Abdelrahim of WHO Sudan gave a presentation on the size estimation exercise undertaken in Sudan last year. This exercise involved efforts to combine old and new data to derive national estimates for MSM and FSWs using a retrospective capture recapture (CRC) approach. Five cities were chosen in which to implement three methods simultaneously, neighbourhood mapping, capture recapture, and multiplier. The mapping was conducted in 5 cities, and data from the mapping were used together with retrospective data from a previous integrated biological and behavioural survey (IBBS) to constitute a capture recapture. The other multiplier (using police data) did not work out. So in the end only two methods were used.

Results from the mapping study gave a range of 0.84% to 1.59% across cities for MSM, and 1.03% to 3.95% for FSWs (as a proportion adult males and adult females respectively). For the CRC exercise, the range of value for MSM was 0.9% to 2.54% across sites, and for sex workers it was 1.04% to 2.98%. In general, when comparing individual cities, the

estimates from the CRC exercise were higher than those from the mapping data (with a few exceptions). So a key question is whether the mapping numbers represent an underestimate, or the CRC numbers represent an overestimate. Depending on the biases, either scenario is possible, but the higher numbers may be less plausible (depending on how broadly MSM and FSWs are defined). The inability to deal with mobility, and the long time elapsed between the two surveys, may have contributed to overestimates in the CRC study. Ultimately the differences cannot be fully explained.

Nonetheless, the Sudan attempt to use retrospective data in this manner is worthwhile for developing crude estimates, and may prove useful in the future, in resource constrained situations.

3.3 Tunisia size estimate

Nissaf Ben Alaya of the Observatory of New and Emerging Diseases in Tunis, made a presentation about how available data in the country were used to determine size estimates for high risk populations for use with MOT and SPECTRUM models. Although the country did not explicitly conduct a national size estimation activity, at the time MOT was done, the existing mapping data (which had been collected to help prepare a sampling frame for the 2011 IBBS), along with multiplier data derived from the IBBS and a unique object multiplier, were used to inform the estimates for both MOT and SPECTRUM. The challenge was that mapping and IBBS data were available in only a few locations, and the estimates from mapping were high (e.g. 2.8 % of males age 15–49 in Tunis were MSM), but the HIV prevalence measured in the IBBS survey was also very high (e.g. 16% in greater Tunis). Using these size and prevalence figures together in MOT or SPECTRUM, would give rise to implausibly high incidence and prevalence figures (given the number of AIDS cases reported in the country).

The proposed solution was to divide MSM into higher risk and lower risk subsets, and apply a higher prevalence to those with the higher risk group (those assumed to have more frequent anal sex and more partners), and a lower prevalence to those with less risky sexual behaviour. The assumption is that the IBBS captures mainly the highest risk subset, so a corresponding size value must be used. For this exercise, 30% of MSM (.98% of males aged 15–49) were considered high risk, and the remaining 70% of MSM (1.82% of males aged 15–49) were put into the lower risk subset. This represents one way to "analyse" size estimation data into a format that is more usable for the purpose at hand.

3.4 Mapping in South Sudan

Gabriele Riedner presented the experience of a large scale mapping study in southern Sudan on behalf of Faran Emmanuel, who could not be present at the meeting. The mapping study had complimentary purposes; to develop national size estimates for risk populations, and to describe the different typologies and organizational structures of key populations.

A method that has already been widely utilized in South Asia, it involved Level 1 mapping with secondary key informants at the regional or zonal level, and Level 2 mapping

with primary key informants at individual hot spots, followed by integration of the results from the two exercises.

The presentation highlighted the richness of the data coming out of the exercise, and the very practical "hands-on" nature of the information it produced, including sizes of different subtypes of sex workers soliciting from different types of venues in different zones. The geographic presentation of the information is also very effective for seeing at a glance how sex workers are distributed across the country, and where the larger and smaller clusters are. The presentation stressed that in order to be useful, the exercise had to be done with adequate investment of time and resources, and with the involvement of many stakeholders (ministry, nongovernmental organizations and most importantly, the community being mapped). The benefits of using a participatory community approach to mapping for laying a strong foundation for good programming, was also stressed.

3.5 Lessons learnt from sub-Saharan Africa about size estimation of key populations at higher risk

Abu Abdul-Quader of CDC Atlanta shared experiences from a lessons learned workshop that included Ethiopia, Ghana, Rwanda, Kenya, Mozambique, Malawi, Cote d'Ivoire and Nigeria.

All of these countries have implemented size estimate activities in the past few years. Most have used direct size estimation methods in selected locations, and they have used combinations of virtually all the methods described in the various guides (census, service-based multipliers, census-based multipliers, mapping and enumeration, network scale-up, Delphi, capture-recapture, etc).

Some of the most important themes and common threads highlighted by Abu Abdul-Quader are mentioned below (although there were many other useful observations that are described in the slides):

- Size estimates of key populations at higher risk are political. They involve stigmatized groups; groups whose existence the country would prefer to deny. To reduce stigma, it is important to conduct size estimation activities, and arrive at consensus, with the involvement of many players (including government, and key population members), to reduce stigma.
- Involving key populations from the beginning, in planning, implementing, and disseminating results, gives credibility and legitimacy to the exercise, and helps provide access to the community.
- No one size estimation method is perfect. They all have problems, and they all have biases. They give different results, which makes them difficult to interpret. So the goal should always be to agree upon a reasonable range.
- Formative assessments are necessary to help decide which method will be "right" for a given country. What works in one country might not work in another. In large degree it's dependent on political will and level of engagement of communities.

- National size estimates are the most difficult so they should not be attempted first. In fact, most size estimation methods are more useful and applicable at the local level.
- Rwanda was the only country in the group which had tried network scale-up at the national level. It turned out to be an expensive undertaking which did not produce very satisfying results. The numbers found for IDUs and MSM were extremely low. It wasn't clear whether this was because the populations don't exist, or because there were problems of transparency using NSU. It was suggested that it might have been helpful (and more useful) to try smaller, more localized methods first.
- Many factors influence the degree to which size estimation studies can succeed. Some
 that are most important are local capacity, political will, rapport with the community
 and key populations, and synergy with donors, government, and development partners.

A helpful summary slide at the end of the presentation gave the "bottom line" on some of the methods:

- Census and enumeration can be straightforward but are costly and likely to miss hidden populations
- Capture–recapture has a long history but can become technical and complex particularly if a third recapture is required
- The multiplier method is widely used and relatively cost-efficient but heavily dependent on the quality of existing data. Using different multipliers can yield vastly different results.
- The network scale-up method can collect data for all groups from one study and does not require exposure of key population
 - Relies upon the calculation of a personal network size which can be complex
 - Not recommended as a stand-alone method.

3.6 Discussion

Following the size estimation presentations, there was a discussion of what UNAIDS and WHO think are the priorities for population size estimates. Gabriele Riedner explained that population size estimation (PSE) is considered as one way to address denial and unwillingness to speak out about the presence of high risk populations in some countries. Conducting size estimation data collection activities and coming up with size estimates, encourages countries to acknowledge what is happening and to act on it by using the information to plan programmes, measure coverage, and show impact.

There was some discussion of how the need to show impact creates a situation where countries cannot get money from the global fund if they cannot show impact, and for that they need size estimates. At the same time, getting national size estimates requires a lot of investment, demands a lot of work, often does not produce good results, and has the potential to divert money from interventions. WHO's main goal is to support countries in doing something to prevent HIV and provide services to people who are at risk and who are infected with HIV. But, they are also driven by Global Fund needs.

So a major point of discussion was about how much it is worth investing in population size estimation, relative to other things. A few people made comments and gave their perspectives on this question:

- Mohammed Abdelrahim explained that the decision to do size estimation in every state in the country (in Sudan) was political, even though technical people understood that it was not necessary. He also mentioned that interventions in Sudan started long before there were any size estimates, or IBBS surveys. However, the need for population size estimation came about because of the need to monitor interventions and measure impact. Now they are planning to do NSU. But they will not cover the whole country.
- Ivana Bozicevic mentioned the example of the triangulation exercise in Souss Massa Draa in Morocco, and the fact that coverage based on size estimates and programme data turned out to be very low, which was something the government was not expecting.
- Sherine Shawky expressed the opinion that it's very important to do size estimates, but unethical to if/when there are no interventions to go with them.
- Abu Abdul-Quader talked about a PEPFAR meeting in 2009, at which there was broad recognition that doing interventions "in the dark" without using size estimates to inform resource allocation and targeting, is problematic and could be challenging.

Ali Feizzadeh made very important remarks about the limited utility of investing a lot of resources on size estimates, given that many countries have very few activities (or plans) to address the needs of high risk populations. Current size estimation methodologies being applied in the region are producing very wide variations (which is itself a problem). In addition, he pointed out that regardless of which of these numbers are used, coverage is still very low (between 5% and 10%). In such a situation, it's not all that useful to get more precise numbers. The current situation of limited resources and capacity to do interventions in the region means that coverage is not likely to increase all that much in the short run. Given the early stage of service provision in the region, it is more appropriate, and a better use of resources, to focus on increasing services. Once progress is made in that direction, we will be in a better position to obtain better size estimates. So while it is necessary to have at least some crude size estimates to guide work (or to have enough information to get funding, or do MOT or SPECTRUM), there is need to be careful about how much to invest. It is important to avoid using limited resources for elaborate size estimation activities that do not add value to efforts to manage programmes and influence policy at the country level. He mentioned that if rough estimation will provide an adequate picture to figure out what we need to do for the next year, then perhaps that is the way forward.

Tobi Saidel concurred with this point, adding that the level of precision required depends on the context in which you will use the information. Cherif Soliman added that size estimates should not be the first step, but should rather be added when programmes already have outreach and are already doing something for the population. Then size estimates can be done "in parallel", but certainly not 1–2 years in advance so that programmes can decide what to do.

Abu Abdul-Quader added that it is never recommended to do size estimation activities alone, just for the sake of doing them. If they can be added to another activity, that is fine. But

HIV prevention activities were conducted for 30 years without size estimates, and while they may make things better, they are not absolutely necessary for action.

3.7 Network scale-up in the Islamic Republic of Iran

The final presentation of the first day was Ali Haghdoost, who shared information on all the research and training being done by the Kerman HIV Hub in the Islamic Republic of Iran to improve the ability to do network scale-up studies. Some specific things mentioned were:

- Studies to improve estimates of "C" (population network size in the general population)
- Use of NSU to measure other things besides sizes of key populations (for example annual incidence of abortion)
- Research to measure visibility and popularity factors.

He also described the research for obtaining national estimates of the size of drug users, female sex workers, and MSM populations using network scale-up, and said that this exercise had been very much appreciated in the country because it allowed for national size estimates, and because it was done in a way that is repeatable. He also talked about how useful the information had been, especially in the case of MSM, where it had helped to start a very useful discussion to advocate to policy makers about the presence of this population.

Some challenges he mentioned in relation to the NSU exercise included:

- Difficulties in determining how to define risk groups, since people's responses are based on judgment (for example, how to differentiate between a woman who is "loose" and a woman who is a sex worker.
- Differentiating between people who were "ever" engaged in risk behaviour as opposed to currently engaged in risk behaviour
- Addressing subnational variation (because sample sizes for the NSU survey are too small to provide meaningful estimates when disaggregated at provincial level).

Discussion

Some concerns were raised during the discussion were about how much money should be invested in NSU, especially given the additional studies that are needed to calibrate the numbers and understand the adjustments. The environment for doing this type of work in Iran has been supportive, but this is unusual and may not be realistic in other countries in the region. One person commented that NSU may be trendy because it allows us to get numbers for high risk populations without having to be in contact with them. Such avoidance can be symptomatic of the discomfort inherent in developing rapport with populations that need services. However ultimately, that rapport is a critical aspect of addressing the needs.

3.8 Population size estimation tool

The second day began with an introduction to the population size estimation tool being developed by Tobi Saidel and Virginia Loo, at the request of WHO and UNAIDS. The main "guiding principles" behind the tool are summarized below.

- The goals for national and local size estimation are not the same and the required level of precision should be guided by the different purposes for which the data will be used at different levels
- Data do not need to be "perfect" to provide the type of information we need to act. The desire for precision must be balanced against the availability of resources.
- Sources of data that can be used for size estimation will tend to be more available in the locations with the highest concentrations of risk groups.
- The process of size estimation is likely to be "iterative", with initial rough estimates serving to focus programmatic efforts in the short run, and more precise data being gathered once programmes are more developed.
- Finally, size estimates are not an end in themselves. Size estimation data only become useful when they are used in the context of an activity like geographic prioritization, specific intervention planning, estimating HIV prevalence at a local or national level, or advocacy. Using size estimates in this way generally requires additional analysis or adjustment of the data in hand.

A fair amount of guidance exists already on the size estimation data collection methods and many countries in the region have begun to implement size estimation activities. However, most countries, including those which have collected data, have trouble using the data for the activities that require size estimates. For this reason, the population size estimation tool focuses on better describing activities requiring size estimates and ways in which countries can use the data they have for those purposes. It also focuses on orienting future data collection in a good direction.

The tool is designed in a way that guides users through the possible situations in which they might need to use or obtain size estimates. These situations are in the form of "frequently asked questions" (FAQ) related to using size estimates for programme planning, geographic prioritization, estimates and projections, and advocacy.

In addition to the FAQs, the tool addresses special challenges for size estimation in the regional context, including 1) how populations are defined, 2) the challenges related to conducting size estimation in a context in which the existence of some risk groups is not acknowledged, 3) confusion about how to count undocumented/illegal foreign residents and nationals who travel to and return from countries where they engage in risk behaviour and are exposed to HIV, 4) addressing risk populations which are not venue-based, and 5) doing size estimates in countries where there is little or no culture of nongovernmental organizations working with key populations.

Finally, the tool includes a decision tree for helping countries decide what to do depending on where they are in the process of trying to obtain size estimation data.

3.9 Discussion on priorities for size estimation

One suggestion was using the population size estimation tool, organize an event, especially for those countries planning size estimation activities, to come together and "apply" the tool:

- Use it to help think through the approach they are planning and factor in things they
 may not have considered, or
- Use it to develop an approach from scratch.

This will be very important because if the tool is just disseminated (e.g. by email) with no follow-up, it is unlikely that countries will really use it. Another suggestion was to maintain a spreadsheet to track which countries are doing size estimation activities, which methods they are using, and what results they found.

Ali Haghdoost proposed the establishment of a regional expert group on size estimation. On this point, Ali Feizzadeh suggested that since the region does not have a technical support facility, and because there are relatively few people who can provide such assistance, that the idea of a separate expert group may not be realistic, but input and advice can continue to be provided to countries on an informal basis.

Ali Feizzadeh made the suggestion that countries which have done SPECTRUM or MOT or other special activities that required them to come up with size estimates, can be asked to share the reports and/or write-ups describing their approach.

4. CASE REPORTING

4.1 Overview of case reporting

Ivana Bozicevic began this session by summarizing the progress to date with case reporting by countries. All countries in the region have some form of case reporting, and in 2011, there were 4263 cases reported by 14 countries, two-thirds of them in men. The cumulative number of reported cases prior to 2011 was around 38 000.

Some of the limitations of reported case data were discussed:

- Reported cases are broken down by mode of transmission. Typically the modes that are reported are heterosexual, MSM, maternal to child transmission, blood and blood products, and unknown.
- Male-to-male transmission is typically not captured (only 2% of all infections in males were categorized as MSM transmission up to 2011, and only 3.5% in 2011 itself).
- All heterosexual transmission is lumped together without distinguishing between commercial and non-commercial heterosexual transmission
- Mode of transmission is "unknown" in a third of reported cases
- There is no reliable information on where transmission is taking place (i.e. inside our outside the country).

There is also not much information or analysis on changes in numbers of reported cases year by year, and also changes in testing patterns year by year. So the understanding of changes in reported cases relative to changes in testing patterns (as the number and profile of people being tested changes), is not being captured.

Other useful pieces of information that come from case reporting are the male-to-female ratios and CD4 counts among newly diagnosed patients. From the male-to-female ratios, we can see that there are still far more males than females being detected. This could be for a variety of reasons (number of reported cases depends on numbers tested, and it is possible that in most countries there are more males than females being tested). However, to the extent that this pattern is real, it suggests that there is more MSM transmission than the reported mode of transmission data would lead us to believe. The data on CD4 counts among newly diagnosed patients allows us to see that most case are still detected at a fairly late stage, with more than 50% already needing antiretroviral therapy at the time of diagnosis.

In conclusion, the reported case data can be a very rich source of information, but case data need to be reported and analysed in a more thoughtful way.

Abu Abdul-Quader shared experiences from other regions of the world on case reporting. In summary, this presentation focused on the very wide range of actionable information that can come from case reporting systems, if the quality of the data is good. However, the challenges of obtaining good quality data are massive, especially less developed countries. Overcoming these challenges will take investment, mainly increasing the number of staff who are available and "capacitated" to record and report the type of information that can be garnered from case data (such as information on who and how many people are infected, where new infections are coming from, what the direction of the epidemic is, and where care and treatment services are required). The ability to obtain such information depends not only on staff, but also well-designed data collection formats and electronic systems to transport data (IT infrastructure).

How much to invest in recording and reporting systems remains as a key question. However, case reporting is a strength of the region. Countries are stronger at case reporting than they are at doing surveys (whereas in Africa, case reporting has largely been allowed to lapse in favour of strengthening capability of doing surveys).

Given the expectation that most countries will not be able to sustain the current pace of conducting "special surveys" to track HIV epidemics in the long run, and given the relative strength of case reporting in the region, strengthening routine reporting systems in the region makes sense. Routine reporting will not solve all problems, but it's an area that can be improved with relatively little investment.

Ard van Sighem_continued the session by sharing information about monitoring of HIV cases in the Netherlands. The system is impressive with information tracked at the individual level about treatment regimens and their effect on CD4 counts at the individual level. Some analysis of the effect of treatment on the course of the epidemic was also shared.

4.2 Using case reporting for HIV estimates

During the second part of the day, Ard van Sighem described several methods that are still in various stages of development, for using reported case data to estimate prevalence of HIV. One which is relatively simple (in terms of data requirements) is based on the relationship between CD4 counts and AIDS. It is based on an understanding of the rate at which people develop AIDS at different CD4 levels. If the number of observed AIDS cases diagnosed at a given CD4 level is known, then the total number of people at that CD4 level can be back-calculated. This method falls short of estimating the total number of HIV infections, but is useful for estimating antiretroviral therapy (ART) need (e.g. number of people with CD4 < 200 or < 350). The method becomes much less precise at higher CD4 levels (because developing AIDS at higher CD4 levels is much rarer). That is why the method cannot be used to estimate the total number of people with HIV.

The other model with good potential is a model that reconstructs incidence curves, based on a combination of any or all of the following (HIV diagnosis, AIDS diagnosis, simultaneous diagnosis, HIV-related symptoms, CD4 counts, and "recent HIV infections" (using viral load testing).

During the discussion, the point was clarified that the model using simultaneous HIV and AIDS diagnosis – as well as the method to reconstruct incidence curves – will work, even if there is a lot of under-diagnosis (i.e. people not tested). The main thing is that there should not be "incomplete" reporting, meaning failure to report AIDS cases among those who have been tested and found to have AIDS at the time of HIV diagnosis.

A second question was about whether the model that reconstructs the infection curve has ever been compared with SPECTRUM. The answer was "not yet". But in the future, if there ever comes a time when we want to recommend that people use this model to replace SPECTRUM, it can only be done after comparing results with SPECTRUM.

The model that reconstructs infection curves has good potential because a) it estimates all infections, not only infections that have progressed to CD4 < 350 or 200, and b) because it does not require a lot of data. It requires only number of cases reported in each year, in each of the CD4 categories. However, it is important to have these data from the beginning of the epidemic. If countries have it only for the last few years, the model won't work (or it will require many more assumptions and have greater uncertainty in the results). Working through how to address this will be the challenge for developing this method into one that can be more widely applicable.

4.3 Case notification

In a final presentation on priorities for strengthening HIV case notification in countries, Laith Abu-Raddad reinforced the importance of maximizing the use of case reporting data, given the climate of diminishing resources, and the fact that the region has such low level epidemics (and therefore less priority on HIV as compared to other diseases).

In his presentation, he "advocated" for standardizing case notification formats, and moving toward an online database that can be shared between countries in the region (which apparently is already in existence in a "pilot" phase). He also talked about the large volume of testing data in the region, and how it is underutilized (e.g. Qatar does half a million tests per year and even though there are many caveats and biases, with such a large volume of data, much useful information can still come out of it).

There was a discussion of how countries need help with using data (e.g. knowing how to communicate key findings to media, policy makers and programme managers).

During the discussions, regarding the suggestion to develop standardized formats and ask countries to use them, Gabriele Riedner reminded everyone that countries have had reporting systems in place for many years, and that this is not the time to start over with new formats.

There was also a long discussion on recording and reporting obstacles (i.e. why it is that data are not reported "well", why there are so many quality issues, etc).

Ivana Bozicevic suggested that one useful activity would be to share examples from countries with good case reporting systems (e.g. Morocco and the Islamic Republic of Iran), showing how they use the data. For example, Morocco has good information on CD4 counts. This could perhaps be done at the next national AIDS programme managers meeting, or at some other occasion.

There was also a discussion about the need to advocate to countries about the importance of reporting. Abu mentioned that it should actually be an issue of national policy and national governments needing to get involved.

Gabriele Riedner mentioned that the regional case reporting system, which has already been through a "pilot' round (in which 14/23 countries actually reported their data), will now become more formalized, meaning that they (WHO), will try hard to 'oblige" countries to submit their data, and that they will bump up the request to the level of the Minister (instead of national AIDS programme managers).

4.4 Discussion on priorities for case reporting

The day ended with a discussion on priorities for case reporting. There was a lot of interest and enthusiasm about the models and methods for using case reporting data together with CD4 counts to estimate populations living with HIV.

• It was clear that the group strongly supports the further development, customization, and testing of a model for estimating incidence and prevalence using reported case data and CD4 counts. Such a model would be especially important for GCC countries, but might become useful for other countries as well.

- There were also suggestions that if such a model could be developed and adapted for the countries in the region, it could perhaps be validated in a country that already has SPECTRUM estimates (such as the Islamic Republic of Iran or Morocco).
- With regard to improving case notification, it does not seem possible to have intensive follow-up with all countries on this issue.
- The possibility of holding a workshop on improving data use was mentioned by Gabriele Riedner, although she cautioned that this type of support is better done with a "hands-on", mentoring type approach.

The group was asked to share ideas and help provide direction about technical and investment priorities (not only for case reporting but for surveillance and strategic information in general), which Ali Feizzadeh and Gabriele Riedner could then use to leverage the limited resources of UNAIDS and WHO to get "buy-in" from other donors

- Cherif Soliman, speaking on behalf of FHI360, talked about their efforts in Egypt to
 gather all projects and nongovernmental organziations (15 of them) working with highrisk groups, to help pilot training approaches. He mentioned that in their experience,
 once something happens in one country, then other countries with similar contexts may
 follow.
- Abu mentioned that although it's difficult for CDC to do large-scale work on (for example) projects like mapping, it might be possible for individual people to be made available for technical assistance.

With respect to the model for estimating incidence and prevalence, participants raised the following points.

- Ali Haghdoost asked whether there might be a possibility of finding financial support for an expert to work in the region on further development of the model
- Ali Feizzadeh mentioned the possibility of CDC getting involved with piloting and testing the model to see how it can be used in non-European countries.
- Gabriele Riedner asked whether there might be interest in piloting this kind of approach
 using one of the Qatar grants, saying also that Global Fund would be unlikely to support
 this kind of activity (unless in conjunction with a specific grant for a specific country).
- Keith Sabin mentioned that UNAIDS might be able to use a small amount of the funding allocated for the reference group to do some modelling work with a country like Morocco or Oman which have CD4 data. (The reference group is interested in filling in some of the gaps, primarily for countries in Western Europe, which generally don't have the kind of data that SPECTRUM requires). Morocco would be a good choice because they also have SPECTRUM outputs to compare to.
- Laith Abu-Raddad mentioned the idea of asking the modelling consortium to put some money into the development of this model.
- Ali Akbar requested Laith Abu-Raddad to write a short proposal to the modelling consortium and/or follow this issue of how we can run a project in one or two countries.
- Laith Abu-Raddad offered that rather than develop a proposal, he could speak to the Modeling Consortium to see if they are interested in this issue, and whether they would

- consider issuing a request for proposals. But he mentioned that it would be important to be sure, before we ask them, whether it will really be possible to get a good proposal.
- Laith Abu-Raddad asked Ard van Sighem whether he would be interested. Ard van Sighem indicated that this would need to go through the ECDC, since he is busy with his work for them.
- Ali Feizzadeh asked whether ECDC envisions a "stand-alone" model like SPECTRUM, which people could be trained to operate independently, or whether everything would have to be done through ECDC. He also asked how "open source" the model would be. For example, if a country wanted to explore some changes in the model based on the local context, would that be possible?
- Ard van Sighem mentioned that there is not yet a user-friendly programme, but there are plans to develop one in the next 1.5 to 2 years. There are not yet any details on what the model will look like, or whether it will be "downloadable", etc.
- Gabriele Riedner suggested that it would be helpful to have a 1–2 page concept note that would help in case we come across groups that are interested in supporting this work. She requested that someone from the exert group help to write a short concept note explaining the rationale behind the model...why it makes sense, etc.
- Ard van Sighem mentioned the importance of involving country experts who really understand what is going on with their data.
- Gabriele Riedner mentioned that it would be good to work with countries which really
 want to work on their estimates. It might be possible to work with those countries on the
 ground and support them to do it.
- Ard van Sighem mentioned that it's also possible to use these methods without CD4
 counts if you have simultaneous HIV/AIDS diagnosis. What is essential is to have some
 way to explore links between HIV and pre-AIDS diagnosis.
- Nissaf Ben Alaya proposed the possibility of having a student from her country (Tunisia) work on this model, saying that she can find someone who is a modeller, who could work together with someone from ECDC.

5. HIV ESTIMATIONS IN THE REGION

5.1 Using SPECTRUM for estimates

Ali Feizzadeh updated the group on the process of using SPECTRUM for estimates and projections, highlighting the following issues and problems.

- The model is designed for countries with either generalized or concentrated epidemics, and requires at least three data points over time for each population included in the model. Countries without the necessary data are advised to use the workbook model instead. However, the workbook provides only a simple snapshot at one point in time. It does not allow for back-calculation of incidence curves, which then allow for estimation of prevalence and ART need (therefore workbook is inadequate for the task at hand).
- Estimating sizes of populations to include in SPECTRUM is also very difficult, especially groups like clients of sex workers
- SPECTRUM uses multiple data points to fit curves for key populations at higher risk (which are the most important in low and concentrated epidemics), but even in those

countries which have multiple data points, they are usually only from a few sites that started relatively recently, generally in the areas with the highest presence of the risk groups. Later expansion to less severe epidemic spots further complicates the ability to use the data for estimates

- When data are sparse, there is little to "constrain" the model. Many curves can fit
 through the same limited data points. In such situations, deciding which curve reflects
 the reality becomes very subjective.
- In concentrated epidemics, a few important risk groups may account for a lot of infections, but there is still the "remaining" low risk population for which we don't usually have trend data. So what to use for that group also becomes a problem. In the absence of antenatal care data, (which most countries in the region, appropriately, do not collect, data from other sources such as blood donors or voluntary counselling and testing sites end up being the only proxy. However, these data are quite problematic, and difficult to interpret.
- Most countries in the region end up cobbling together whatever data they can to produce estimates which may or may not be valid.
- We can improve the curves by making some "common sense" decisions when we see that the curves produced with our "raw or unadjusted" data do not make sense, but this process is again highly subjective.

The question therefore, that Ali posed to the group, was how SPECTRUM could be used in the region in a meaningful way.

Discussion

Keith Sabin reiterated that UNAIDS' goal for the estimation process is to maximize the quality and quantity of data to inform national estimates, (disease burden and treatment need). But this is a global goal and certainly not a priority for every country. (In most countries, HIV is not high priority because it's not in the top 5, 10 or even 20 diseases). The benefit of countries engaging with the process, is that they are forced to look at surveillance programme data with a more critical eye than they might otherwise. We have the choice of asking the reference group to consider models that can more easily be used with the type of data we have in the region. Or, we can continue to try to find better approaches for calibrating data and setting parameters upfront. But in any case, we will still need 3 data points regardless. SPECTRUM only requires incidence numbers to be plugged into it. (In Asia they use AEM to generate incidence curves, but those types of data are generally not available in countries of the region). It might be more fruitful to push for a model that estimates incidence using the reported case data. This should be a recommendation back to Geneva (easier for UNAIDS to request than WHO because UNAIDS has a more global approach, where WHO focuses on high burden countries).

Ali Haghdoost made several suggestions about how we can improve estimates:

• Continue to push for better quality data, even though the rewards are not very immediate (limitations of the model which requires at least 3 data points over time).

- Use proxy data from countries with more data, for countries which have less data, but similar population types (e.g. use data from Kurdish parts of the Islamic Republic of Iran for Kurdish parts of Iraq, or data from southern Saudi Arabia for Yemen). But this is very political so would be quite difficult.
- Use regression modelling, linking prevalence of HIV (as an outcome) to independent variables (e.g. demography, GDP, age group), from countries which have data, to produce "acceptable" estimates for those countries which are struggling to have data (this would be politically sensitive).

Laith Abu-Raddad raised the issue of whether we are really using all the data we have, saying that countries (even national AIDS programmes) are often surprised to see all the data they have (This comes out when countries engage in MOT exercise).

There was a lot of discussion on the need to better analyse data into a form where they can be used for the various exercises (like SPECTRUM and MOT). Nissaf Ben Alaya mentioned that putting "crude" data into these models does not produce acceptable results, and it is always necessary to revise and reanalyse data before being able to use. Tobi Saidel commented that improving data does not always mean collecting more data. Very often it means simply analysing the data differently.

Gabriele Riedner talked about the positive and negative effects of pushing countries to use SPECTRUM. On the positive side, it encourages countries to examine and use their data. On the negative side, it takes a lot of time which may distract them from more important things they need to be doing. IBBS surveys for key populations have been a "game-changer" in the region (in the sense that they can encourage action for groups that have been ignored in the past, (like MSM). But these survey data may not be so useful for SPECTRUM, even though SPECTRUM might give the impetus for doing the survey in the first place.

Ali Feizzadeh showed the group some examples of HIV estimation from the Global Burden of Disease website, which uses totally different models to do estimates, and pointed out that the "rankings" they have for "number of years of life lost due to HIV" in different countries are not really rationale. So his point was to say that the models we use are "no worse" than some other models.

Keith Sabin mentioned that UNAIDS will accept estimates done using other models. But there are not many appropriate models that exist. Up to now, the models that use case notification methods have not been considered as promising (outside of Europe), because they require data that most of the countries don't have. (Europe is different because of more sophisticated linked patient record systems). However, he thought that if we can manage to use the model for two countries in the region, this might encourage Geneva to take it more seriously.

5.2 Discussion: priorities for improving HIV estimates

Participants discussed what concrete efforts could be made to further develop the incidence from case report data models. Gabriele Riedner asked who were the "main owners"

of the models. Ard van Sighem is very involved in spearheading efforts on the second model (which is the one that is of most interest).

With regard to how to help countries better analyse their data for use with estimates, Keith Sabin noted his disappointment that after ten years of the estimation process, which was intended to encourage careful consideration of data (as opposed to the top-down approach that used to be used by Geneva), there is still so much sloppy work. He also talked about the lack of a culture of ongoing use of data with constant review and updating of models, and "faulted" UNAIDS for not having succeeded better at making this happen.

Some suggestions of way to help countries prepare their data for estimation included the following.

- Use the MOT process or triangulation process, in combination with one-on-one technical assistance to help countries look more closely at their data.
- Organizing "pre-workshop" homework in a better way. Very few countries routinely come together and go over the data. We have to work harder on that. If people wait until they are sitting in a workshop to look at their data...and then do estimates based on what little they bring to the workshop, it's really a "disservice" to the country.
- There was a lot of discussion on whether it makes more sense to do this in a workshop type setting, or on a one-to-one basis. Finally it was concluded that efforts are needed before, during and after the workshops to improve the use of the data.

Ali Haghdoost had some ideas about activities to support the efforts to improve data. He suggested the regional expert group work together to write: 1) a paper about recent estimations in the region which can be published in a scientific journal; and 2) a comprehensive report for countries with detailed explanations of how estimations are being done (e.g. check the results in different rounds, compare results between countries, triangulate in other sources of information (e.g. from the global burden of disease database, or MOT). Producing such a report would require asking countries to respond to a survey. He felt that this would potentially encourage countries to participate in the process in a more meaningful and active way. In the meantime, partners could use this time (the two years until the next estimate) to work with countries one by one so they are better prepared to do estimations next time.

Gabriele Riedner felt that rather than what Ali was suggesting, that it would be more achievable to think of supporting countries to better analyse and make sure of their data in a more in-depth way (like what was done in Tunisia). She thought we should focus on supporting the countries that are ready to do it (e.g. Sudan). From the WHO side she could imagine supporting 1–2 more countries to do more in-depth analysis of their data. But supporting a big regional survey, and trying to communicate with all the countries, only to find out that many of them require technical assistance, would not be doable for them.

• Ivana Bozicevic mentioned that the triangulation process in one region of Morocco (which included two workshops) took around 6 months (with about 2–3 months of a consultant's time), which she said is quite short compared to other triangulation

projects. She thought maybe that was because it was regional instead of national. And she mentioned that it had been very useful for the local level.

- Gabriele Riedner commented that it is unlikely that many donors would be willing to support such a lengthy process. It would be difficult to find donors who would support a one-month exercise in two countries, let alone a 6-month process in one region of one country.
- Ali F expressed his views that while it is fine to do this kind of intensive approach, that in the end you only get 3–4 countries with more usable data. He mentioned that the stronger countries which have more data and more capacity to begin with, end up being the ones that receive the most support, because they are more likely to engage in the process. But it should be the other way around, because from a regional perspective, all countries need to be "on par".
- Gabriele Riedner pointed out that it will be difficult to work on a "region wide" basis, saying that she favoured the idea of the country by country approach. Even by prioritizing only three countries a year, eventually all will be reached. It is also possible that along the way, the capacity to do more will evolve.
- Cherif Soliman reminded the group that sometimes a small effort can go a long way (e.g. back in the days when there was no voluntary counselling and testing and no surveillance in this region, a workshop in Cairo "jumpstarted" the process). But such kinds of workshops could not be only for technical people. National AIDS programme manager and similar types were needed who have the power to do something with the information. So, an initial effort in 3–4 countries can become an epidemic. (Diffusion effect). Once some countries start doing it, then other countries will copy.
- A few people commented on the need for countries which do estimates, to publish the
 results. This can "grab attention" and maybe even start a healthy competition and also
 attract academia.
- Tobi Saidel made a plug for non-scientific publications, which can sometimes have more reach.
- Ivana Bozicevic suggested doing a workshop for all the countries, where you guide them through the process and the methods for triangulation, and then they can go back to their own countries and do it.
- Sherine Shawky said that the challenge is not to attract academia, but to get policy makers on board. She also pointed out that while academics read scientific publications, most policy makers do not.

Keith Sabin summarized "where we're at". EPP/SPECTRUM is a problem in the region. Ultimately, there is not enough data. There is need to look at large screening programmes (blood donor, prison, pre-marital testing) and see how the data might be reasonably used to inform regional models and understanding of epidemics in countries where other data are lacking. Programmes might think about a "return" the Know Your Epidemic (KYE) approach (i.e. push MOT/triangulation/KYE". An emphasis coming out of this meeting is also to work more closely with Ard van Sighem to solve some of our dilemmas where survey data do not exist.

In a response to aquestion from Keith Sabin about whether the five-day workshop format should be continued, Gabriele Riedner thought it was very valuable, if for no other

reason than to have direct contact with all the countries...and to allow country to share with each other. Tobi Saidel thought the two extra days were not all that helpful (i.e. very insufficient amount of time to engage countries in the analytic process required to prepare the data for the model). Nissaf Ben Alaya agreed, saying that there is a need for an interactive process with the people who know the data better in the country. So it's important to have interactive workshops in the country. Ali A suggested that key actions be taken before, during and after the meeting. He suggested that it is very important to communicate with countries what type of information is needed several months before the meeting. This will help to ensure that at least some arrive with good information, and also that they send the best possible participants. (Editorial note: The best way to achieve this may be to ensure that at least some people who come to the workshop are those who participated before, because it is usually an iterative process.).

Keith Sabin noted that for the Panama workshop, there was a series of webinars with slides presented up front. This was really helpful, though potentially difficult in the region due to language issues. The pre-workshop process would greatly benefit from a more proactive approach up front.

In answer to a question from Keith Sabin regarding prisoners and blood donors, and also voluntary counselling and testing and other service-related data, it was noted that these are relatively important datasets used in this region that are not used so much in others regions. Gabriele Riedner asked whether it might be helpful to have some kind of guidance on how to consider these types of data (e.g. blood donors, pre-marital screening, in-country migrants, migrants going out of the country). Keith Sabin suggested that it might really save time and confusion if we developed some guidance on whether/how these data can be used, and how to calibrate them, etc). He thought it might be something that we should bring to the reference group (i.e. John Stover and Tim Brown).

Ivana Bozicevic mentioned that there is a similar issue related to how to sample clients. Some important take-home points from the session included models for generating incidence curves. Participants noted the need to push for further development of a model that can generate incidence curves using the type of data countries already have, or can more easily obtain (reported cases and CD4 counts). These models should be used in a couple of countries. It was noted that countries need more "lead" time to understand the type of data they will need to do their estimates and the type of "pre-analysis" that will be required. This could possibly be accomplished through webinars, or one-on-one mentoring, or possibly some type of workshop on triangulation or MOT.

6. ACTION POINTS

In this session, Gabriele Riedner and Ali Haghdoost presented their suggestions about follow-up activities and priorities coming out of the meeting with respect to the three thematic areas of the meeting.

Population size estimation

Suggestions for WHO/UNAIDS

- Finalize and disseminate guide/tool for population size estimation
- Hold a side meeting of national AIDS programme managers to introduce the tool
- Consider holding a workshop for selected countries to be organized by Kerman Knowledge Hub
 - Introduce and orient them on the tool
 - Work with these few countries (maybe 6 or so) on their country situations, the questions they are struggling with and how to proceed

Suggestions for the expert group

- Review population size estimation in the region and prepare an analytic report (scientific paper) for possible journal publication
- Workshop (same as mentioned above)

Case reporting

Suggestions for WHO/UNAIDS

- WHO to introduce revised regional case reporting forms to the ministers of health for annual reporting to the Regional Office
- Encourage countries to revive/revise and strengthen their case notification systems
- Develop/disseminate generic case notification protocols and generic case notification reports for countries to use as templates
- Provide direct technical support to selected interested countries (e.g. for developing case notification protocols and reports, and implement them). As countries are being encouraged to do this better, they may request help.

HIV estimation

Suggestions for WHO/UNAIDS

- Ask the reference group to provide guidance on the use of information for proxy groups such as blood donors, premarital screening, migrant testing, prisoners; guidance on use of prisoner and voluntary counselling and testing data or other programme data (in the model); and guidance on what to do about clients of sex workers (i.e. how to modify/adjust data to use in models).
- Liaise with ECDC regarding the piloting of the estimations model based on HIV case notification and CD4 count data in countries of the region, starting with 1 or 2 countries in the region.
- Provide direct technical assistance to selected countries to 'know your epidemic' in the context of HIV estimation exercises.

 Work more closely with other institutions involved more closely on estimation (like IHME).

Suggestions for the expert group

- Develop a concept note for piloting the use of HIV case notification data for HIV estimations in the region (Laith Abu-Raddad to take the lead on this).
- Produce analytical reports and publications on HIV estimation in the region.
- Support selected countries to produce analytic estimation reports (i.e. something that
 goes beyond the table of outputs to also discuss how the data were adjusted, modified,
 etc.).

General

- WHO/UNAIDS to request CDC for direct provision of technical assistance to countries.
- Identify a strategy to develop capacity of regional institutions/experts to provide technical assistance (i.e. to institutionalize technical assistance to countries).
- Work with FHI on piloting certain approaches for training key populations at higher risk.
- Liaise with ECDC on estimation using reported cases.

As a group, efforts could also focus on developing a few papers on priority topics. The following people volunteered to take the lead/participate in the development of three papers.

- Size estimation (Ali Haghdoost to lead, Tobi Saidel and Nissaf Ben Alaya to contribute)
 First draft to be ready by end of September 2013.
- Case reporting (Ivana Bozicevic to lead: Ali Haghdoost and Laith Abu-Raddad to contribute) First draft by mid-August.
- Estimation Look into what countries have put into their models and analyse) Everyone to contribute. First draft December 2013 (Soodabeh Navadeh to lead).

Annex 1

PROGRAMME

24 June 2013		
	Session 1	
	Opening session	
09:00 – 09:30	Opening Session Opening remarks	
	Objectives and expected outcomes	
	Review of agenda	
	Introduction of participants	
	Session 2	
	Activities of the regional expert group since the last meeting	g
9:30 - 10:30	Special supplement of Journal STI	Laith Abu Raddad
	Definitions of key populations	
	Discussion	
	Session 3	
	on size estimations (PSE): methodologies and their application	in the region
11:00 – 11:30	Overview of population size estimations and methodologies used in the Region (15 min)	Tobi Saidel
11:30 – 13:00	Examples from Sudan, Tunisia, South Sudan (15 min each) Discussion	Sudan (Mohamed Sidahmed) Tunisia (Nisaf Ben Alaya) South Sudan (Faran)
14:00 – 15:00	Lessons learnt from other regions (15-30 min) Discussion	Abu Abdul-Qader (CDC)
15:00 – 16:00	Review of network scale-up methodology; Experience with implementation in the Islamic Republic of Iran (30 min) Discussion	Ali Haghdoost

25 June 2013				
09:00 – 10:00	Presentation of PSE tool and discussion	Tobi Saidel		
10:00 – 10:30	Discussion on priorities in the area of population size estimations (What should UN partners prioritize? What can the expert resource group contribute?)	Tobi Saidel		
Session 4				
Case reporting				
11:00 – 11:45	Overview on case reporting in the region (20 min)	Ivana Bozicevic		
	Discussion	Gabriele Riedner		
11:45 – 13:00	Case reporting in the Netherlands (10 min)	Ard van Sighem		
	Use of case reporting data in other Regions (max 30 min)	Abu Abdul-Qader		
	Discussion	(CDC)		
14:00 – 16:00	Using case reporting for HIV estimations (max 45 min) Discussion	Ard van Sighem		

16:00 – 17:00	Discussion on priorities for strengthening HIV case	Laith Abu Raddad
	reporting in the region (What should UN partners prioritize?	
	What can the expert resource group contribute?)	

26 June 2013		
	Session 5	
	HIV estimations in EM/MENA	
09:00 – 10:00	Key issues with HIV estimations in the region (15 min) Discussion	Ali Feizzadeh
10:00 – 11:00	Discussion on priorities for improving HIV estimations in the region (What should UN partners prioritize? What can the expert resource group contribute?)	Keith Sabin
11:30 – 12:30	Conclusions Closure of the meeting	Gabriele Riedner Ali Feizzadeh Renu Chahil Graf Jaouad Mahjour

Annex 2

LIST OF PARTICIPANTS

Dr Ivana Bozicevic Executive Director WHO Collaborating Centre for HIV Surveillance Zagreb CROATIA

Dr AliAkbar Haghdoost Head HIV Hub WHO Collaborating Centre Kerman University of Medical Sciences Kerman ISLAMIC REPUBLIC OF IRAN

Dr Soodabeh Navadeh Distance Educational Manager HIV Hub WHO Collaborating Centre Kerman University of Medical Sciences Kerman ISLAMIC REPUBLIC OF IRAN

Dr Sherine Shawky Research Professor Social Research Centre American University of Cairo Cairo EGYPT

Dr Laith Abu-Raddad Associate Professor Weill Cornell Medical College Qatar Foundation – Education City Doha QATAR

Mrs Hiam Chemaitelly Research Specialist Weill Cornell Medical College Qatar Foundation – Education City Doha QATAR

Dr Ard van Sighem Senior Researcher Stichting HIV Monitoring Amsterdam THE NETHERLANDS

Dr Nissaf Ben Alaya Associate Professor of Preventive Medicine and Epidemiology Observatory of New and Emerging Diseases Tunis TUNISIA

FACILITATORS

Dr Tobi Saidel Director, PEMA Consultants, LLC Epidemiologist Lyons, Colorado

OTHER ORGANIZATIONS

Centers for Disease Control and Prevention

Dr Abu S. Abdul-Quader Epidemiologist Global AIDS Programme Atlanta UNITED STATES OF AMERICA

FHI 360

Dr Cherif Soliman Country Director for Egypt Cairo EGYPT

UNAIDS SECRETARIAT

Dr Keith Mitchell Sabin Senior Advisor UNAIDS Geneva SWITZERLAND

Dr Ali Feizzadeh Regional Strategic Information Advisor Regional Support Team for the Middle East and North Africa (RST-MENA) Cairo EGYPT

WHO SECRETARIAT

Dr Jaouad Mahjour, Director, Division of Communicable Disease Control, WHO/EMRO Dr Gabriele Riedner, Regional Adviser, HIV/AIDS and Sexually Transmitted Diseases, WHO/EMRO

Dr Mohammed Abdelrahim, HIV Surveillance Officer, WHO Sudan



World Health Organization Regional Office for the Eastern Mediterranean P.O. Box 7608, Nasr City 11371 Cairo, Egypt www.emro.who.int