Strengthening Capacity for Leveraging Existing HIV-related Data among Key Populations to Assess Data Gaps and Prioritize Specific Data Collection in Malawi

26 April 2018, Blantyre Malawi

Objectives

1. Review evidence on key populations from Malawi, including a review of quality of available data

2. Introduce new methods for leveraging existing data, including small area estimation and dynamic transmission modeling

3. Identify gaps in knowledge and programming that impede effective intervention in key populations

The new Global Fund 2017-2021 strategy and PEPFAR 3.0 increasingly focus on data to improve evidence-based responses to HIV epidemics, in terms of both the content and scale of HIV programs. Traditionally, in the context of generalized HIV epidemics, most countries have focused almost exclusively on the "general population" with minimal attention towards characterizing the needs of specific key populations. When the majority of new infections occur in general populations, interventions for that population are crucial. Nonetheless, even in countries where HIV prevalence is high in the general population, there are key populations that have disproportionately high risks of HIV acquisition and transmission, such as sex workers, men who have sex with men, and injection drug users. These key populations are important for countries to consider because they represent cost-effective opportunities for prevention; their contributions to the epidemic are much higher relative to their overall population size. Indeed, no epidemics will end unless these key populations are also targeted for prevention efforts. To date, efforts to intervene in key populations have been hindered by: 1) lack of high quality data on epidemiology of transmission and prevention, and 2) limited efforts to incorporate existing data on key populations into country plans.

List of Attending Organizations

- CDC
- CEDP
- District Health Offices, Ministry of Health
- FHI360 Central Office
- Johns Hopkins University
- Kamuzu College of Nursing
- Lighthouse
- Malawi College of Health Sciences
- National AIDS Commission
- Pakachere IHDC
- Population Council
- UNC Project
- USAID
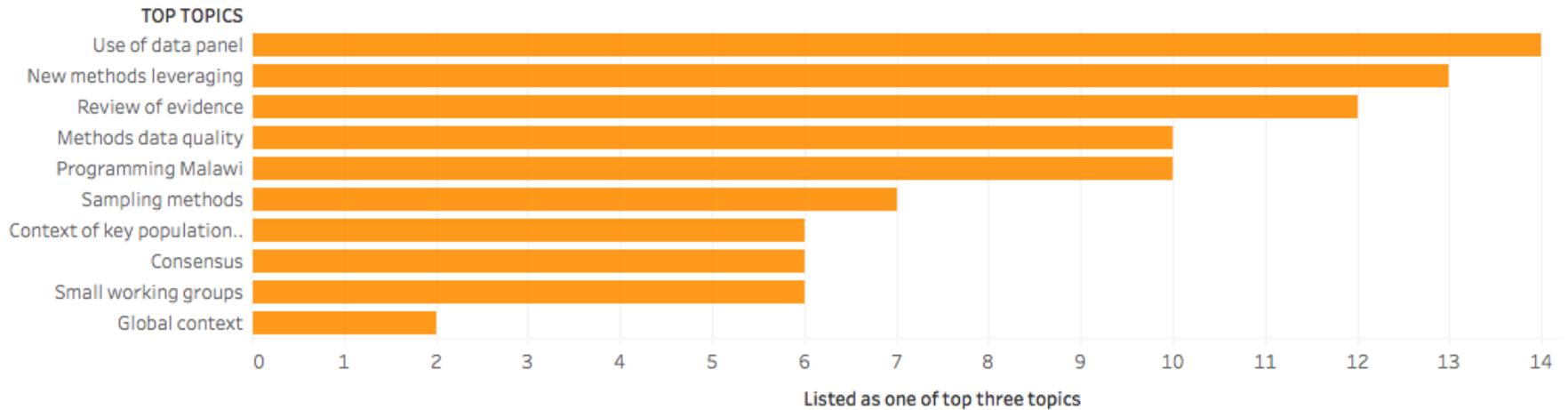- YONECO

Agenda: 26 April 2018

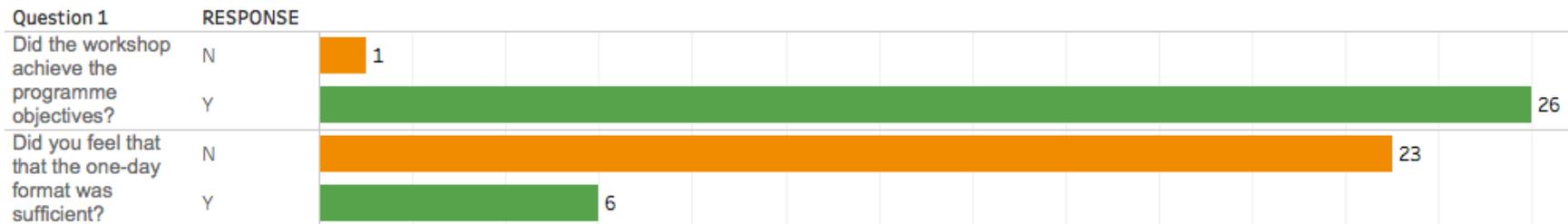| Time	Name of talk	Presenter
8:30-9:00	**Registration – Coffee**	
9:00-9:10	Welcome by Ministry of Health	Ministry of Health
9:10-9:25	Objectives of the workshop	Stefan Baral, Johns Hopkins University (JHU)
9:25-9:50	Use of data for decision-making	**Panel discussion**
9:50-10:10	Global context of HIV-related vulnerabilities among key populations	Stefan Baral, JHU
10:10-10:15	Clarifications	
10:15-10:30	Context of key populations in Malawi	Joel Suzi, National AIDS Commission (NAC)
10:30-10:35	Clarifications	
10:35-10:50	**Morning Break**	
10:50-11:10	Key populations programming and data in Malawi	Louis Banda, Linkages
11:10-11:20	Clarifications	
11:20-11:50	Sampling methods for studies of key populations	Sheree Schwartz, JHU
11:50-12:00	Clarifications	
12:00-12:30	Review of methods for assessing data quality	Amrita Rao and Sheree Schwartz, JHU
12:30-13:00	Review of the evidence from key population studies in country with assessment of quality of evidence	Amrita Rao, JHU
13:00-13:10	Clarifications	
13:10-14:10	**Lunch**	
14:10-14:30	New methods and tools that leverage existing data	Stefan Baral, JHU
	-Front-facing tool and small area estimation	
14:30-14:50	Overview of PLACE method in Malawi	Shawn Aldridge, Linkages and NAC
14:50-15:00	Clarifications	
15:00-15:30	Small working groups to identify and prioritize key data gaps	Emily Gurley, JHU
15:30-15:50	**Afternoon break**	
15:50-16:20	Building consensus from small working groups	Emily Gurley, JHU
16:20-16:50	Priorities and next steps	
16:50-17:00	Closing of the workshop	Joel Suzi, NAC

Workshop Evaluation

At the end of the workshop, participants were given an evaluation form **(Appendix 1)** to give feedback on the contents, organization, and relevance of the workshop. We received feedback from 32 of 43 total attendees (74.4%). Based on feedback from these 32 attendees, the workshop received an overall mean score of 4.0/5, where a score of 1=poor and 5=excellent. When asked to select the top three topics discussed during the day's presentations, participants indicated the 1) panel discussion on data use for decision-making, 2) new methods for leveraging existing data, and 3) review of evidence from key population studies with assessment of quality of evidence, as the most interesting or useful.

TOP TOPICS

Topic	Value
Use of data panel	14
New methods leveraging	13
Review of evidence	12
Methods data quality	10
Programming Malawi	10
Sampling methods	7
Context of key population..	6
Consensus	6
Small working groups	6
Global context	2

Listed as one of top three topics

Overall, participants felt that the workshop did achieve the programme objectives, but would have preferred a slightly longer workshop, indicating preference for a 1.5 or 2-day workshop.

| Question 1	RESPONSE	Value
Did the workshop achieve the programme objectives?	N	1
	Y	26
Did you feel that that the one-day format was sufficient?	N	23
	Y	6

About half indicated that the workshop met their expectations, with another 40% indicating that the workshop somewhat met their expectations. Only 1 participant reported that the workshop did not meet his/her expectations (blue) and 1 indicated that the workshop mostly met expectations (orange).

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Did the workshop meet expectations?

YES: 55%

Somewhat :38%
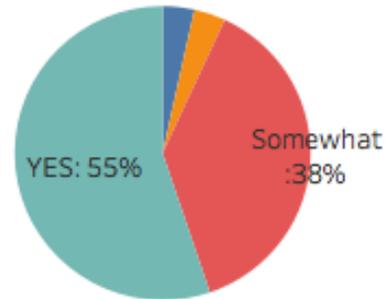
About half reported that the knowledge and information gained during the workshop would definitely be useful/applicable in their work, with no participants indicating that the information was not useful.

Will the knowledge and information gained be useful/applicable in your work?

Mostly: 34%

Somewhat: 17%

Definitely: 48%
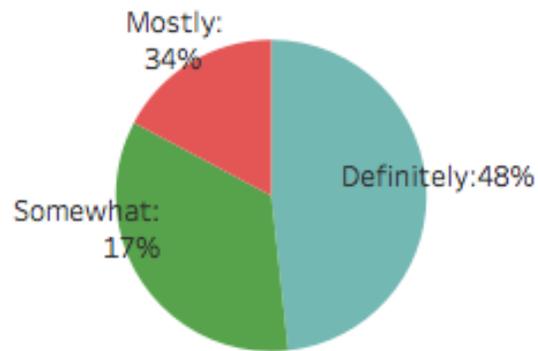
The workshop received a score of 4.3/5 for organization. Some **suggestions** included:

1. Would prefer a longer workshop and more time for methods-based presentations
2. Would like to see more group work, group discussions
3. Would like to have received the final agenda earlier
4. Would like to have clearly differentiated between what takeaways are for program implementers versus decision-makers

Notes

Use of data for decision-making: Panel Discussion

Melchiade Ruberintwari, LINKAGES; Shawn Aldridge, NAC; Joel Suzi, NAC; Collins Mhango, USAID; Beth Deutsch, USAID

- Importance of using data to inform programs goes beyond generating data to report to donors and other key stakeholders who are asking about it, but also need to consider how to translate the use of data into real-time programmatic responses
- Lots of data is being generated in programs, and need to think about the quality of program data and how data can be repurposed to further inform and refine programs
- Balance between quantity and quality of data
  - How to balance program targets with collection of quality, representative data?
  - Think about incorporating qualitative data – how can it be used to make sense of quantitative findings
  - In order to understand discrepancies between research and program data, it is necessary to think about how targets are set and what yield actually means

- Scientific presentation of data is different than a communication strategy of data that is actually meaningful to program implementers
  - Need to better understand how to package data that is usable by those on the ground
  - Otherwise, can have all the available data but no one will use it
  - Relatedly, we need to be able to better answer the question of *who is using the data to make decisions*? And *whose data is it?*
    - This will help us determine the structure and detail required.
      - *Data use cascade*
- Strategies to promote better understanding of what various indicators mean
  - Data collectors and synthesizers need to *understand* the data in order to make optimal use of it and in order to improve on it
  - Need to clearly communicate to M&E managers what different indicators mean
  - Can we use indicators in conjunction? (e.g. Clients of FSW positive yield and how this impacts HIV negative FSW)
    - Creatively using data that are already being collected
- Need for cross-partner data sharing
  - Are some organizations generating data that can be used by other implementing partners? Sharing data is essential for strengthening programming? Is there a central platform we can use?
- Flexibility in data collection and use based on local context is important

Global context of HIV-related vulnerabilities among key populations

Stefan Baral, Johns Hopkins School of Public Health

*Full presentation available in shared dropbox folder. Some notes below:

- For female sex workers, main intermediary for HIV acquisition and transmission is clients of FSW and NPP
- For MSM, we often find there is no main intermediary. Acquiring and transmitting HIV to one another [15-18% globally, regardless of region]
- Incidence among KPs really not declining, if anything increasing (especially in LMICs)
- Higher cumulative HIV incidence among younger men
- Late HIV diagnoses: among all populations other than MSM, we're doing better in terms of earlier diagnoses. But among MSM, we continue to do poorly globally in early identification
- Transgender people: really limited data; transgender women have the highest burden of HIV of any group globally

QUESTIONS FROM AUDIENCE:

1) Racial difference in black and white MSM in Atlanta -- elaborate on the underlying reasons?

--Access to prevention and treatment care. Have higher untreated HIV and higher viral load --> driven by network related characteristics, not differences in sexual behavior

2) Treatment as prevention

--Difference between individual and population level effects. Important to also think about treatment as a longer term issue, and how we continue to engage people over time.

3) Started transgender program in Malawi: any experience from other settings in programming for transgender populations?

--Stigma and complex dynamics are common across the world. Similar programs, but have to think about differences in implementation (TRANSit as a resource)

4) Why are we not lining up in terms of what we're seeing in the program data for MSM and what the research data shows?

--Prevalence does include known infections, yield does not include known infections. Translating prevalence studies into yield studies -->still important to think about how to set meaningful targets and other strategies for reaching MSM living with HIV

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Context of key populations in Malawi

Joel Suzi, NAC

Full presentation available in shared dropbox folder. Some notes below:

- Rationale: Why the focus on KP?
  - UNAIDS estimates 40-50% of all new HIV infections may occur among KPs and their immediate partners
  - Towards ending the epidemic, Government of Malawi recognizes addressing the needs of KPs as a priority effort towards the overall reduction of new infections
- HIV prevalence among KPs [62.7% among FSW, 18.2% among MSM]
  - Issues in service saturation levels: program data is showing lower MSM HIV prevalence as compared to study estimates of MSM HIV prevalence
- MDHS and MPHIA = General population HIV prevalence
- Driving determinants of high vulnerability include: stigma, discrimination and unfavorable social and legal environments
- Objectives of KP programming in HIV/AIDS Response: full list provided in slideset
  - Improving access to quality facility-based and outreach services
  - Strengthening effectiveness and continuity of services
- High level targets
  - 90% of MSM, FSW, TG receive standardized package of prevention services

- o 90% of FSW consistently use condoms and lubricants with casual male clients (self-reporting and commodity based assessments)
  - o 90% of MSM and TG women consistently use condoms and lubricants during high-risk encounters
  - o Universal knowledge of KP human rights
- Some key bottlenecks though: full list provided in slideset
  - o No national standard package or guidelines
  - o Data issues
  - o Weak linkages and referral
- Opportunities in the management of KP program in Malawi
  - o Developing and available expertise
  - o Increased NGOs working in KP programs
  - o Shifting legal frameworks
- Current priority actions: full list provided in slideset

QUESTIONS FROM AUDIENCE:

1) Self-testing and PrEP, incorporating new technologies into programming

--Government of Malawi has approved use of self-testing. Key populations are central to the implementation and roll-out of PrEP and self-testing

--Using other platforms, including WhatsApp groups, to further reach and answer key questions that may seem to be answered but are not fully understood

--Law is not yet friendly to key populations, but leadership is. This has facilitated the utilization of new technologies

2) Issues with saturation

--Need to make the case for expanding coverage to other districts, with the understanding that yield may be going down in districts that we've been engaged in for a long time

-->prioritizing high-burden districts

Key populations programming and data in Malawi

Louis Banda, LINKAGES FHI360

- Partnering with MOH to deliver comprehensive HIV services: primarily MSM, FSW, PWID, and transgender people
  - Availability of services
  - Demand for services
  - Strengthened monitoring systems
  - Package of services (KPs, clients of FSW, AGYW)
  - Service delivery models
- Geographical scope: six districts
  - Mzimba North; Lilongwe; Mangochi; Machinga; Zomba; Blantyre
- Package of services
  - Includes prevention messages, condoms, testing, family planning, PMTCT, linkage to care
- Service delivery modalities
  - Drop-in Centres; Outreach clinics
  - Hybrid: facilities where service provision largely depend on other stakeholders (public and private health facilities)
  - Static: LINKAGES-supported clinics which provide services to KPs
- Partners and stakeholders
  - Outreach teams; District health offices, private clinics, Baylor Children's Foundation; Central hospitals, Dream Lab, Lighthouse
- Key results and emerging data available in slideset
- Key reasons for success
  - MOH leadership and buy-in
  - DHO/DHMT and DEC engagement and ownership
  - Agreement to estimate DICs and KP safe space
  - Provision of medical supplies
  - Supportive supervision to the DICs

Some additional points:

- Since LINKAGES is now tracking cohorts: need to separate those who are already engaged versus those who are just joining the program
- Important to understand that yield is linked to saturation
- Importance of tackling and taking into account legal framework that is not conducive to key populations
  - Cases brought to the Courts; but may need to consider this as a primary intervention and continue to push to work with other groups in the government. Government indicates engaging police in better handling of key populations

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Sampling methods for studies of key populations

Sheree Schwartz, Johns Hopkins School of Public Health

- Full population enumeration represents the gold standard
- But in the real world, we can't enumerate everyone and so have to take a sample
- For key populations, no sampling frame exists, and so we have developed non-probability methods to reach KPs, including
    - Network-based
    - Venue-based
    - Facility-based
    - And Others

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- Facility-based recruitment: simple, fast; those engaged in services likely different than those not engaged in services
- Venue-based sampling: efficient, no need for complete roster and approximates random cluster sampling. It requires a *complete mapping* of places where population found and requires weighting, because of unequal probability of sampling
- PLACE method: see later presentation given by Shawn Aldridge
- Snowball sampling: accrue rapidly using social networks; not recommended unless limited by time and resources
- Respondent driven sampling (RDS): final sample will be similar to the population of the network from which you are sampling; strong assumptions and need for adjustments
  - Need to run diagnostics to ensure assumptions are met
- WebRDS and other innovative strategies exist
- How to decide which method to use?
  - Research question; generalizability; efficiency; ensure that reporting and analytic methods match the design

Review of methods for assessing data quality

Amrita Rao, Johns Hopkins School of Public Health

- The purpose of this presentation is to introduce the methods used in the quality assessments of available data.
- Having access to data is important
    - For understanding the problem, identifying gaps in current problems, informing development of new programs, making the case for investment
- Deciding whether or not to use certain data should depend on availability of, but also quality of the data
- To this end, a quality assessment tool was developed to evaluate the quality of available evidence for key populations
    - Prevalence, incidence, care continuum, PSEs

- Scores are based on performance in three main categories: study design, study implementation, and study-specific criteria
- Differentiating between target, source, and sample population
- In evaluating the study design, we should consider whether or not a study is an accurate and representative picture of the population of interest
- In evaluating study implementation, we should consider whether those who chose to participate were similar to those who did not participate
- Finally, in evaluating indicator-specific criteria, we should consider whether testing measures, statistical adjustments, and other analytical factors are consistent across person, place, and time
- *Worked example provided in dropbox folder*

Review of the evidence from key population studies in Malawi with assessment of quality of evidence

Amrita Rao, Johns Hopkins School of Public Health

- Review of the current and available evidence for key populations in Malawi
  - Just to note that these were the data we were able to gather and collate, but also realize that there may be data either being collected in real time or that have been previously reported (but unpublished) that we may not have had access to. If there are other data sources that you know of that seem to be missing here, we'd love to hear about them.
- In an ideal setting, we'd have information on key indicators for key population groups
- In reality, there are gaps in the available data
- To help facilitate use of available data and identification of gaps where further data collection is needed, a data repository is being developed of all available data on key populations. This data repository is intended to be accessible and sustainable
- Data pulls are customizable and can include some or all of the available data, but again, include data on these primary indicators.
  - Link to google form for data requests: https://goo.gl/forms/cbc94Qlii3BUZYmB2
- Data gathered here are based on a larger systematic review and focuses primarily on articles published between 2006 and 2016. A preliminary search was done to update this for more recent articles.
- Female sex workers
  - The repository identified 7 sources that were published between 2011 and 2014 for FSW. Just to note these 7 sources are not necessarily from 7 distinct studies of FSW and some of them are just additional publications from the same study.
  - For estimates of prevalence, we identified two main sources.
  - No incidence of HIV data was identified as available for FSW.
  - As for the care continuum, we identified one fair source of data which indicates that about 50% of about 138 FSW living with HIV in Lilongwe were virally suppressed.
  - One national estimate of population size among FSW estimated that there are about 14000 FSW. Both capture recapture and enumeration were used to develop this estimate.
  - Data from the study disaggregated to the district level, estimating about 1800 FSW in Lilongwe and 1100 FSW in Blantyre.
  - Another size estimation activity was conducted in 2011 among FSW which used Capture-recapture in 10 districts and estimated about 19000 FSW nationally.
- MSM
  - The repository identified 10 sources that were published between 2007 and 2017.

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- Prevalence estimates are available for 7 main cities and towns from two studies: one a multisite study conducted between 2011 and 2014 and the other a multi-country study, with focus sites in Blantyre and Lilongwe, in 2008.
- No incidence of HIV data was identified as available for MSM.
- From the same multisite study, HIV care continuum data for MSM were identified. Only about 25% of MSM living with HIV had had a recent HIV test, and 0.2% had ever been initiated on treatment. While there was no reported viral suppression data, these data still received a score of good based on our quality assessments.
- Size estimation activities were conducted as part of the same study, but not published in the peer-review. This study estimated that MSM make up about 1.84% of the male population 20-39 years old in Malawi.
- Similar to the FSW estimates, district-level estimates are also available from the country report.
- For People who use drugs, we were not able to identify any information on our key indicators.
- For transgender people
  - We identified a single estimate of prevalence that disaggregated previously collected data on MSM to get at prevalence among transgender women. The study based on data collected in Lilongwe between 2011 and 2012 found that 16% of transgender women were living with HIV.
- Similarly, for incarcerated populations, we were not able to identify any available data.

New methods and tools that leverage existing data

Stefan Baral, Johns Hopkins School of Public Health

Approaches to population size estimation and opportunities for leveraging existing data

- Population size estimation can be broken into two distinct phases
  - Phase I: local, direct size estimation
  - Phase II: extrapolation from areas with local/direct size estimates to regional or national level
- Phase-I approaches include survey-based approaches that are derived from methods from ecology and animal behavior
  - Can also include routine or program data based approaches
- Small area estimation: one form of Phase II size estimation
  - To produce reliable estimates for where only small samples or no samples are available
  - The key idea is to borrow information from other areas that have more samples
  - Cost/scientific rigor spectrum
- Phase II approaches include
  - Expert opinion, simple and stratified imputation, regression, more complex models
- Malawi SAE example
  - Makes use of data from PLACE 2016, 2014 Malawi BBSS Report, and 2014 Enumeration
  - Makes use of factor analysis and auxiliary data from MDHS to predict PSE of FSW in districts where direct data collection was not done
- Takeaways
  - There is a need to advance methods for both extrapolation and small area estimation for population with limited data
  - Need to evaluate the utility of digital PSE
  - Ongoing development of small area estimation models

Dynamic Transmission Modeling

- Modes of transmission studies have relied on deterministic, static models in the past
    - Push to incorporate dynamic transmission modeling for KPs and population attributable fractions to better understand dynamic sexual partner types and impact over time
- Parameters include ART and suppressed VL
- Long term vs. short term contribution of condomless sex work
    - This is where the dynamic transmission model shows vastly different results than the more traditional model

Global.HIV Front-Facing Tool

- Online interactive tool designed to facilitate access to a range of different types of data for over
    - 150 countries
    - Country-specific dashboards with unique information on key indicators
    - Mapping component that gives the user the ability to access statistics by country.
- Directly links to all available data collated in our larger systematic review
    - Prevalence, incidence, Treatment cascade, Size Estimates
- When clicking on each country, a country-specific dashboard will appear
- Data visualization specifics
    - For both prevalence and incidence, the user will be able to see separate graphs with time on the x-axis (binned by the Year), and percentage on the y-axis.
    - For treatment cascade, the user will be able to access a bar chart with each of the below indicators representing a separate column:
        - 1)Previously diagnosed
        - 2)Linked to care
        - 3)On treatment
        - 4)Virally suppressed/undetectable

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Overview of the PLACE method in Malawi

Shawn Aldridge, NAC

- PLACE – rapid assessment method for identifying/providing
  - Areas/sites likely to have sexual partnership formation patterns
  - Characteristics of patrons at those sites
  - Nature of sexual networking
  - Reach of prevention efforts/interventions
  - Data to inform design and targeting of interventions
- Previous PLACE studies
  - 2003, 2006, 2008
  - Latest: 4th and first national in scope (20 districts, 3 cities)
- Full PLACE methods includes
  - Finalization of protocol and preparations
  - Data collection in selected local areas
  - Use results to improve programs
- Main objectives
  - Identify and map locations
  - Estimate sizes of KPs
  - Identify gaps in service delivery
  - Use results for action planning
- Outcome of venue visits: generate list of hotspots, and conduct programmatic mapping
- --PLACE II: all sites were visited, not all site interviews were conducted
- PLACE FSW PSE and Site walk validates estimates (treating site validation walk as the gold standard)

Some stats:

- 20 districts & 3 cities mapped

- 3727 Community Informants identified venues

- 4103 venues verified operational (PLACE I: 2018; PLACE II: 2085); 5259 estimated operational

- 2635 FSWs interviewed (PLACE I: 1500; PLACE II: 1135)

- 638 MSM & 38 TG women interviewed

- 79% MSM report sex w/ both men & women; 18% men only

- 75% MSM use cell phone / 38% use social media daily

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- 17% MSM met new sex partner online/phone app last 3 months
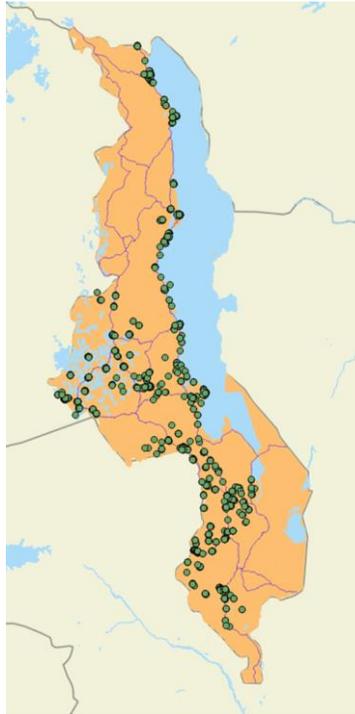
Taken from presentation given by Shawn Aldridge on 26 April 2018.

- PLACE estimates suggest the value in reaching MSM through social media
- PLACE is stronger method for FSW because out publicly; but may not be the best metric for estimating MSM
- Interesting new development: getting a list of venues, looking at individual risk factors and drilling down to see if we can target
    - Use programming information to verify the estimates

Working Groups and Consensus Building Activity

Emily Gurley, Johns Hopkins School of Public Health

Local workshop participants (excluding JHU facilitators) went through an activity to brainstorm on ideas for key epidemiologic data gaps and come to consensus on those that were most important to close, in order to be successful in their mandate to end the HIV epidemic among key populations in Malawi. The activity used a participatory approach to consensus building.

First, participants were put into groups of 5 randomly and asked to take 5 minutes to brainstorm their own ideas for epidemiologic data gaps. Participants listed those ideas individually. Then, each small group decided on a reporter for the group, and that person went one by one through the group and asked each person to name one epidemiologic data gap that they considered to be a priority. Each member should name only one gap each round, and each data gap should be a novel one for the list. This continued until there are no new ideas to share from the group. At the end of this exercise, the group had a list of all the ideas for priority data gaps to address. Then, based on that list, the small group decided amongst themselves which from that list were the highest 3 or 4 priorities for their work.

To come to a consensus among all workshop participants about priorities, the activity facilitator used a flipchart to list the priorities identified from the groups. The facilitator went group by group to ask each to name one, and only one, of their data priorities that were not already on the list, until all of the data gaps prioritized by groups were listed. The list was read aloud to the group, and priorities were combined if they were very similar. Next, workshop participants voted to come to a consensus about which of the suggested data gaps were the most important. All participants had 3 votes. The facilitator read each data gap and the participants who wanted to vote for that data gap raised their hands and the number of votes was counted. The data gaps with the greatest number of votes were considered the highest priorities for the groups.

In total, the groups listed 14 data gaps as possible priorities, and these covered a wide range of topic areas. Ultimately, 3 data gaps received substantively more votes than the others, including more evidence on systematic studies of the prevention and treatment cascade, population size estimates for various MSM sub-groups, and basic data on other key populations, such as transgender populations, male sex workers, and people who use drugs.
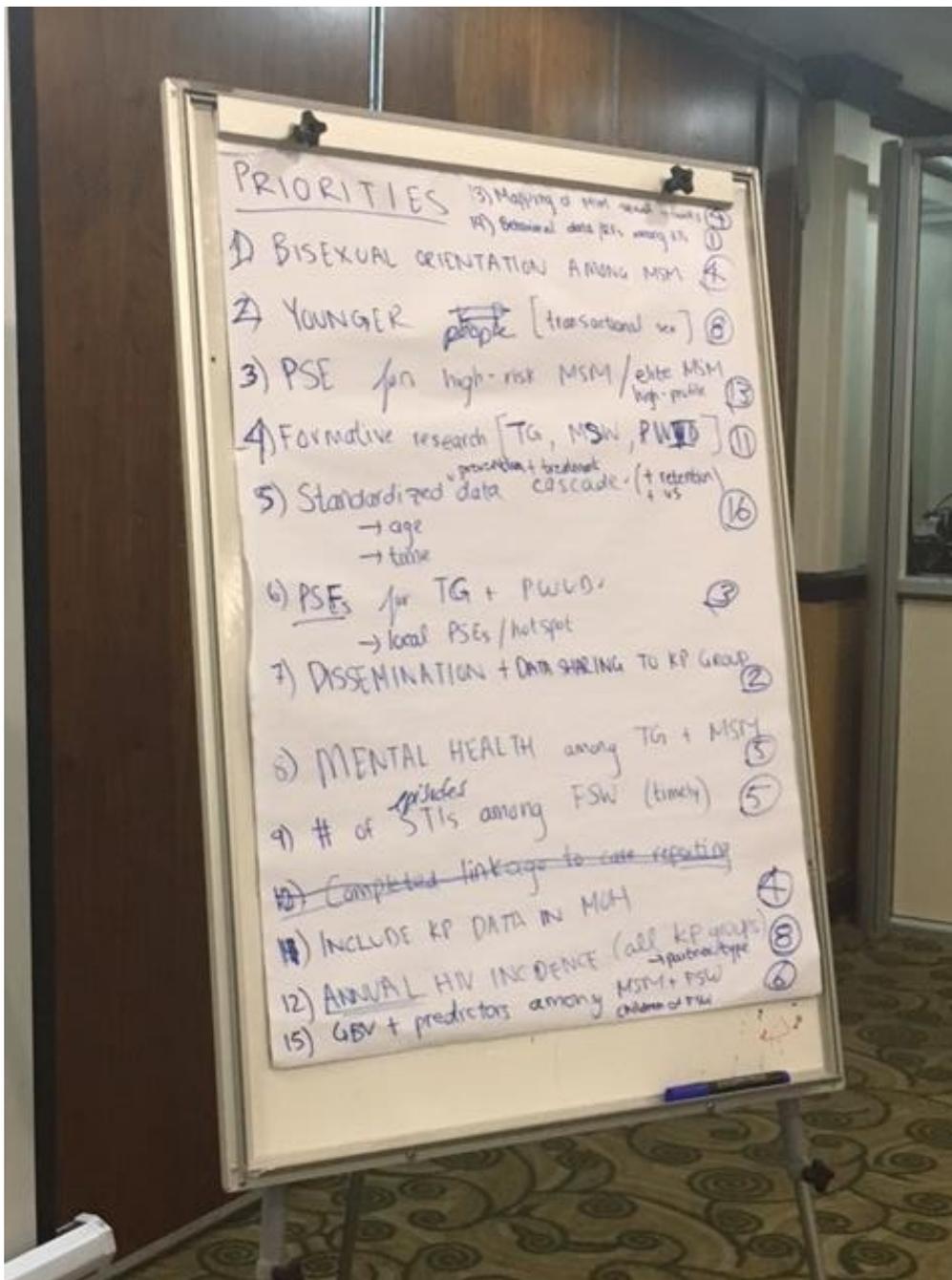
Main Priorities Identified

1. Standardize prevention and treatment data cascade - **16**

      a. Including disaggregation by age and time

2. Population size estimation for different MSM risk groups - **13**

      a. High-risk

      b. Elite or high-profile

3. Formative research for other KP groups [TG, MSW, PWUD] - **11**

4. Younger people and transactional sex - **8**

5. Annual HIV incidence for all KP groups - **8**

6. GBV and predictors among MSM, FSW, and children of FSW - 6

7. Mental health among TG and MSM - 5

8. Number of STI episodes among FSW, more timely numbers - 5

9. Sexual orientation among MSM – 4

10. Including KP data in MOH database - 4

11. Mapping of MSM sexual networks - 4

12. Population size estimation for TG and PWUD, including local estimates - 3

13. Dissemination and data sharing to KP groups - 2

14. Behavioral data and risk factors among KPs – 1

Through operations research, Project SOAR will determine how best to address challenges and gaps that remain in the delivery of HIV and AIDS care and support, treatment, and prevention services. Project SOAR will produce a large, multifaceted body of high-quality evidence to guide the planning and implementation of HIV and AIDS programs and policies. Led by the Population Council, Project SOAR is implemented in collaboration with Avenir Health, Elizabeth Glaser Pediatric AIDS Foundation, Johns Hopkins University, Palladium, and The University of North Carolina.