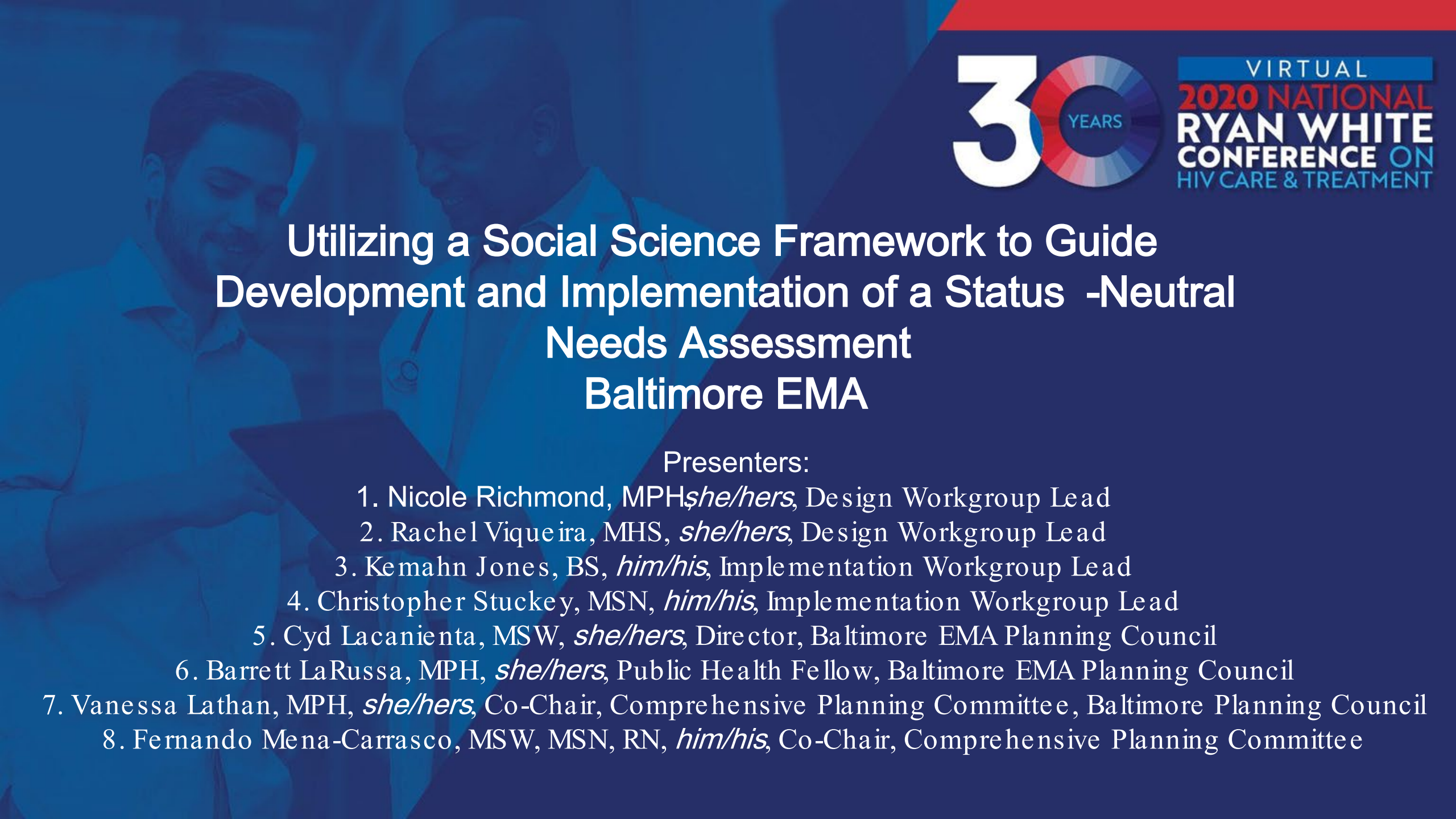

VIRTUAL 2020 NATIONAL RYAN WHITE CONFERENCE ON HIV CARE & TREATMENT

Utilizing a Social Science Framework to Guide Development and Implementation of a Status -Neutral Needs Assessment Baltimore EMA

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Disclosures

Nicole Richmond, Rachel Viqueira, Kemahn Jones, Christopher Stuckey, Cyd Lacanienta, Barrett LaRussa, Vanessa Lathan, and Fernando Mena-Carrasco have **no relevant financial or non-financial interests to disclose.**

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Commercial support was not received for this activity.

Learning Outcomes

At the conclusion of this activity, participants will be able to:

1. **Explain Modified Data Mapping Process** for public health needs assessment.
2. **Describe the matrix-based social science framework developed to lead stakeholders** through the modified Data Mapping process for public health needs assessment purposes: what is known, what is not sufficiently available (time/population/validity), and what the community wants to know.
3. **Describe the iterative foundational processes to engage stakeholders** in developing a needs assessment survey ensuring transparency and continued engagement.
4. **Apply project philosophies in creating protocols for survey design/administration**, establishment of partnerships, hiring of staff, and other activities to develop an implementation plan that achieves survey recruitment goals.
5. **Recognize common challenges of designing and implementing** a needs assessment survey and implementation methodology and identify solutions for these challenges in their own jurisdictions and organizational settings.

Philosophy - Part I

- **HIV-Status Neutrality:**
  - Assess needs among Marylanders along the HIV care continuum.

- **Equity**:
  - Salient questions of lived experiences by key populations and implemented by interviewers who share a common voice for the diverse communities.

- **Cultural Humility**:
  - Members were grounded in the philosophy of cultural humility
    - Awareness of personal and cultural biases
    - Sensitivity to significant cultural issues faced by others
  - Awareness of one's own privilege

Philosophy - Part II

- **Collaboration**:
  - Bring together a diverse body of stakeholders to best inform the content, implementation, and results of the needs assessment.
- **Active Participation**:
  - All voices offer expertise of experience.
- **Collective ownership**:
  - Disseminated governance and decision making - not one voice more important than another's.
  - The culmination for this entire process belongs to everyone.

History of Planning Council

- The Baltimore-Columbia-Towson metro area was one of the EMAs funded early in the history of the Ryan White Program, when the original legislation was passed in 1990.
  - 2021 will mark 30 years for the Planning Council as a regional planning body as defined under the Ryan White Act.
- Planning has historically been based on the documented needs of people living with HIV/AIDS -- using utilization and surveillance data points.
- Paramount to planning process:
  - Conducting a consumer needs assessment survey regularly (**last in 2013**).
  - Needs Assessment process led by the Comprehensive Planning Committee, a standing committee under the Planning Council.

Purpose of Needs Assessment

- Broad-based community engagement is a tenet of the Ryan White planning process.
  - Survey design/implementation process; accounting for and elevating the voices of 6 Maryland counties in the Baltimore EMA.
  - Set precedent for outreach to all EMA jurisdictions in future assessments, initiatives.
- Target individuals who are undiagnosed, vulnerable to HIV, or seropositive.
  - Improve what we know about the health of Marylanders across the HIV care continuum.
  - Inform HRSA- and CDC-funded planning, including Ending the HIV Epidemic plans.
  - Inform future community and stakeholder engagement.

Purpose of Needs Assessment

Criteria for application of survey results:

1. Inform programmatic activities, funding allocations, and future program policy;
2. Use in social marketing, outreach; and,
3. Support ongoing and expanded engagement with all stakeholders, and especially community partners with lived experience.

Survey Workgroups

- Broad-based community engagement is a tenet of the Ryan White planning process.
- Survey design/implementation process coordinated, included, and elevated the voices of Marylanders.
- Under the leadership of the Comprehensive Planning Committee, two survey workgroups formed:
  - Survey Design
  - Survey Implementation

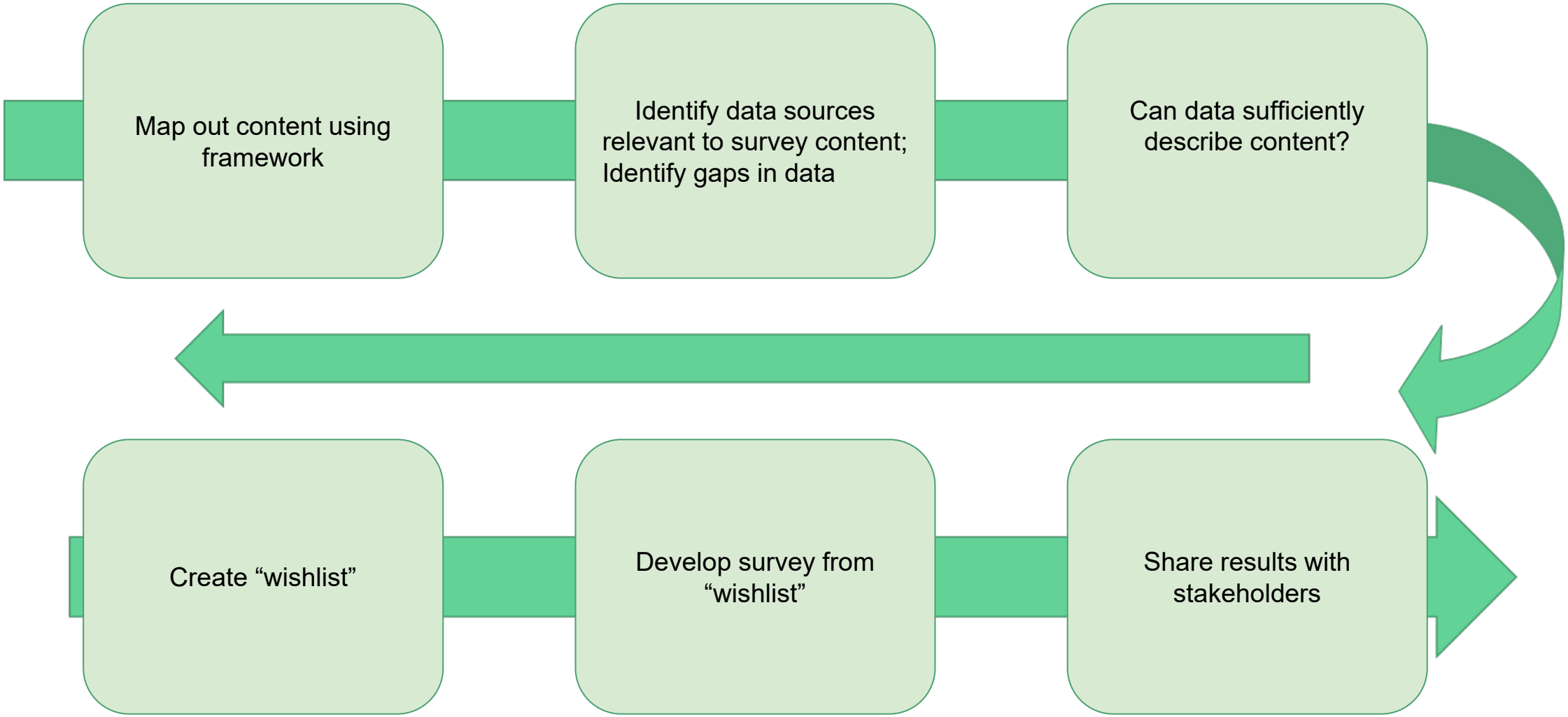
Survey Workgroups

- **Survey Design Workgroup**
  - Led by trained social and infectious disease epidemiologists.
  - Survey refinement was a transparent, iterative process of stakeholder engagement and feedback confirmation.
  - Stakeholders included jurisdictional representatives, and community members with intersectional lived experience.
- **Survey Implementation Workgroup**
  - Led by a trained nurse, a community health educator, and an epidemiologist.
  - Survey implementation included a formative assessment to enumerate a comprehensive roster of venues and subsequently engage community partners.
  - Stakeholders included jurisdictional representatives, and community members with intersectional lived experience.

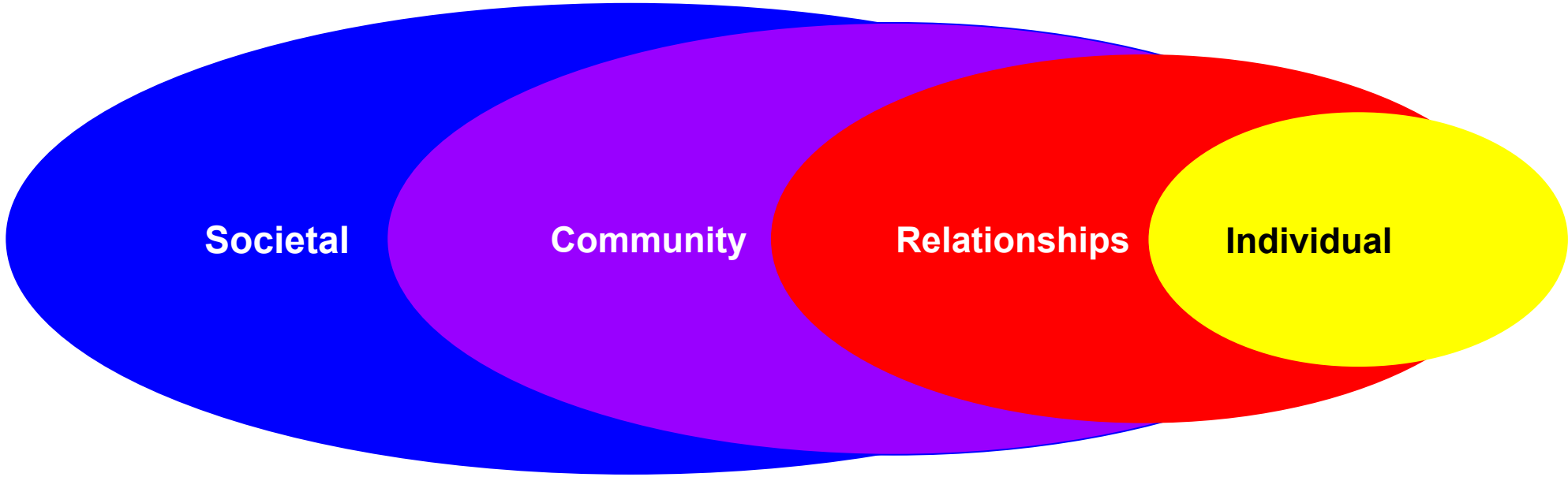
Survey Design

Group goals, considerations, & framework

Design Process and Timeline



Framework for Mapping out the Survey Content



Framework and Mapping out Content

HIV Care Continuum Stage: Population Goals for each stage						
	General Population	**History of behaviors with high probability exposure & HIV status unknown**	**Tested, result is non-reactive**	**Diagnosed, Not in Care**	**Diagnosed, In Care, Not Virally Suppressed**	**Diagnosed, In Care, Virally Suppressed**
Social Ecological Model	Decrease probability engaging in behaviors that increase HIV exposure. Promote community based resources for population to promote resiliency in engaging in behaviors that increase HIV exposure.	Reduce frequency of behaviors that increase HIV exposure. Get tested for HIV. Establish health-supporting behaviors protective of HIV exposure.	Reduce frequency of behaviors that increase HIV exposure. Get tested for HIV, at frequency following best practice. Prescribed PrEP. Maintain continuity on PrEP.	Enter into care. Support sex partner/ IDU network testing. Support sex partner/ IDU network prescribed PrEP. Establish health-supporting and -seeking lifestyle.	Be virally suppressed. Support sex partner/ IDU network testing. Support sex partner/ IDU network prescribed PrEP. Enhance self-efficacy in health-supporting and -seeking lifestyle.	Empower continuity of care to maintain viral suppression.
Society						
Community						
Social Network						
Individual						

Identifying Available Data and Gaps in Data

The topics within the matrix were categorized in three ways:

1. **Data is available and sufficient**
   a. Developed summary measures and created community indicator table
2. **Data is available and insufficient**
   a. Tried to find appropriate proxy data
   b. If no proxy, prioritized for survey inclusion
3. **Data is not available**
   a. Prioritized for survey inclusion

Community indicator table was also useful to contextualize survey responses

Discussing and Evaluating our Progress

- **Group meetings**
  - In person and over the phone or video chat
- **Utilizing information & data to make decisions**
  - Framework
  - Community indicator table
- **How can the needs assessment contribute to the existing**:
  - Research?
  - Programmatic efforts addressing HIV in the BEMA?
- **“Parking lot”**
  - Topic areas and ideas that could not be feasibly included in the survey
  - For future discussions with the planning council

Creating a "wishlist" of Survey Questions

- All group members chose a topic area
- Asked to find relevant survey questions
  - Emphasized validated tools
- Co-chairs organized question submissions
- Edited and pared down list in group meetings based on utility for:
  - Programmatic activities
  - Policy
  - Mass media campaigns (social marketing)
  - Community-based organization partnerships
- Quality control questions
  - Asked questions to survey administrators to understand their experiences

Sampling Distribution of Target Groups

	Anne Arundel	Baltimore City	Baltimore County	Carroll County	Harford County	Howard County
Estimate: Undiagnosed HIV 13+ (n)[1]	158	1280	417	18	60	79
Estimate: Undiagnosed HIV rate/100,000 pop 13+[1]	32.7	250.7	59.6	12.6	28	29.5
PLWH and have unsuppresed viral load (n)[1]	449	3624	1092	50	177	219
HIV Exposure Category for Diagnosed PLWH (MI estimate)						
MSM (% (n))[1]	46.7 (635)	31.8 (3,509)	37.0 (1,331)	46.5 (73)	42.3 (218)	42.0 (286)
IDU (% (n))[1]	13.1 (177)	30.7 (3,386)	17.4 (625)	18.5 (29)	13.8 (71)	9.4 (64)
MSM & IDU (% (n))[1]	3.3 (44)	5.2 (575)	3.3 (120)	4.6 (7)	1.8 (9)	3.1 (21)
Other (% (n))[1]	1.9 (26)	1.3 (139)	2.0 (72)	1.9 (3)	4.3 (22)	1.8 (12)
Heterosexual contact (% (n))[1]	34.7 (471)	30.8 (3,404)	40.1 (1,442)	28.5 (45)	37.1 (192)	43.4 (296)
Not identified (% (n))[1]	0.4 (5)	0.2 (23)	0.2 (7)	0.0 (0)	0.8 (4)	0.3 (2)
County of residence at time of HIV diagnosis						
PLWH (n)[2]	1,251	12,120	3,186	146	460	609
HIV prevalance/100,000 pop 13+[1]	259	2373.8	455.2	101.9	214.4	227
Ratio (1 PLWH:n residents 13+)[1]	1:386	1:42	1:220	1:981	1:466	1:440
Current county of residence among people living with HIV						
PLWH (n)[2]	1,358	11,036	3,597	158	516	681
PLWH %Δ in residence[1]	9% increase	9% decrease	13% increase	8% increase	12% increase	12% increase
HIV prevalance/100,000 pop 13+[1]	281.1	2161.5	514	110.3	240.5	253.9
Ratio (1 PLWH:n residents 13+)[1]	1:356	1:46	1:195	1:907	1:416	1:394
PLWH recent viral load test (%)[1]	76.8	78.6	78.8	71.5	75.6	77.7
PLWH without viral suppression, Median VL count (n)[1]	10,450	11,600	8,645	40,700	14,900	4,330

[1] SFY 2019

[2] RCY 2018

Sampling Distribution of Target Groups

	Anne Arundel	Baltimore City	Baltimore County	Carroll County	Harford County	Howard County
Target Demographics						
Gay and Bisexual Men (23%)	34	84	40	29	33	33
Young Black Gay and Bisexual Men (11%)	16	40	19	14	16	16
Young Latino Gay and Bisexual Men (11%)	16	40	19	14	16	16
Youth (13%)	19	47	23	17	19	19
Persons who inject drugs (15%)	22	55	26	19	21	22
Transgender women (14%)	21	51	24	18	20	20
All others (13%)	19	47	23	17	19	19
Sum	**147**	**365**	**174**	**127**	**143**	**144**

Presenting to Stakeholders

- **Pre-Pandemic Process**:
  - Created a summary document describing survey domains
  - Presented final version to all members of the survey design group
  - Presented to the Planning council for final approval
    - Officially closed design process
    - Survey submitted to IRB
- **Post-Pandemic Process**:
  - Reopened design process with all stakeholders
    - Proposed and explored implementation modifications
  - Survey submitted to MDH IRB again
    - Adjusted protocol approved June 2020

Pretesting

- **Assessing**
  - Survey flow
  - Time to completion
  - Functionality of skip logic
  - Wording of questions
- **Internal**
  - Work group members
  - MDH employees
- **External**
  - Planning council members
  - Allies in Philadelphia and Washington D.C. EMAs

External Pre-test Questions

1. Did you notice any confusing or hard to understand questions while taking this survey? [Categorical: Yes, No]
   - If yes, → For the questions you can remember, can you describe BOTH the question and the part that was confusing or hard to understand? [Open text field]

2. Did you notice any questions that were offensively worded? [Categorical: Yes, No]
   - If yes, → For the questions you can remember, can you describe BOTH the question and the part that was offensive?

3. Did the survey "flow" well overall? (Were there any transitions that did not work well?) [Categorical: Yes, No]
   - If No, → Can you describe where in the survey the transition or flow did not work well? [Open text field]

4. Thinking about the time it took to complete the survey, what is your impression of how much time it took? [Likert scale: Too long, Long, Average length of time, Short, Too short]

1. During this survey you were asked about your needs. Did you feel that this survey asked you about needs that are important to you? [Categorical: Yes, No]
   - If No, → What needs did the survey miss? [Open text field]
   - If yes, → Are there other needs you have that you feel were not asked about in the survey? [Open text field]

2. Would you recommend the survey to anyone? (friend, co-worker, partner, family member, neighbor, etc.) [Categorical: Yes, No, Don't Know/Unsure]

3. Please share any other feedback you would like about this survey testing experience, or the survey. We are happy to learn more from you. [Open text field]

Survey Implementation

Group goals, considerations, & framework

Historical Context

- Historically, the majority of needs assessment participants have been Baltimore City residents.
  - *Reasonable assumption*: PLWHA from the surrounding counties seek care in Baltimore City.
- With this newer approach, efforts were made to actively recruit from EMA jurisdictions outside Baltimore City.
  - A total of 6 Maryland jurisdictions/counties engaged and represented.

Key Populations

- Youth
- Gay and bisexual men
- Young Black gay and bisexual men
- Young Latino gay and bisexual men
- Persons who inject drugs
- Transgender women

Approach: Venue-Based Sampling

Initial Implementation Plan

- **Survey sites**: partner organization facilities, public spaces, community events, etc.
- **Scheduling planner**: spreadsheet of target survey numbers by site and date, to ensure meeting of sample sizes for key populations
- **Daily tracking of demographics** and geographic survey distribution to direct implementation efforts and potential recruitment of new survey sites

Emergency/Disaster (COVID-19)

- **Survey sites' modified role**: advertise and recruit remote survey opportunity, can assist in scheduling
- **Modified scheduling planner**: will assist in meeting of sample sizes for key populations
  - Participants will have the option to call in and take the survey at that time
- **Unchanged: Daily tracking of demographics** and geographic survey distribution to direct implementation efforts and potential recruitment of new survey sites

Stakeholders, Partnerships, and Venue Selection

Stakeholders and partner organizations contribute to survey planning, advertise the survey to their networks and clients, and have the opportunity to serve as "survey sites." Recruitment of partner organizations is an ongoing process.

- **Community members**
  - Patients and non-patients of the Baltimore EMA
- **Community Based Organizations**
  - Jacques Initiative
  - Baltimore Safe Haven
  - Transgender Response Team
- **Universities/Colleges Partnerships**
  - Coppin State University *(HBCU)*
  - Morgan State University *(HBCU)*
  - University of Maryland
  - UMB (Baltimore)
  - Johns Hopkins University
- **Local Health Departments** (Sexual Health/STI/HIV Clinics, PrEP and needle exchange teams)
  - Anne Arundel County
  - Baltimore City (County)
  - Baltimore County
  - Carroll County
  - Harford County
  - Howard County
  - + LHD sub-grantees and local partners
- **Maryland Department of Health**
  - Human resources, database management, IT device setup and management, and IRB.

Survey Advertisement

Initial Implementation Plan

- **Social media** and location-based mobile applications such as Jack'd, Adam4Adam, Grindr, Scruff, and/or Hornet
- **Flyers** (physical and digital) administered by partner organizations
- **Word of mouth** advertisement from partner organization staff to clients
- **Community events**

Emergency/Disaster (COVID-19)

- Greater emphasis on **digital advertisement**, such as social media, location-based mobile applications, electronic newsletters, etc.
- **Flyers** at essential businesses and partner organizations that provide essential services
- **Word of mouth** (limited)
- Advertising at **community events**
- **Virtual community events**/town halls

Participant Scheduling

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Initial Implementation Plan

- **Scheduled surveys:** Staff at partner organizations to schedule clients to take the survey. Interviewers administer survey at scheduled time and location.
- **Walk-in:** Interviewers to administer some surveys on a "walk-in" basis at certain partner organizations, community events, and in public spaces.

Emergency/Disaster (COVID-19)

- Staff at partner organizations may still schedule clients to take the survey, though all surveys will be administered remotely.
- Potential participants may also call the interviewer team directly, and can either do the survey then (virtual "walk-in") or schedule a time to take the survey later.

Scheduling systems and all participant contact information are kept separate from survey data at all times.

Survey Administration

Initial Implementation Plan

- **Who?**
  Clients of local health departments and CBOs, community event participants, and members of the public.
- **Where?** Interviewer administers the survey with clients in private spaces at the facility, event.
- **How?**
  Participant records responses using survey tablet. Interviewer reads the survey out loud/records responses, if needed.
- **When?** All hours.
- **Transportation** to survey and food provided as needed.

Emergency/Disaster (COVID-19)

- **Who?**
  Increased access for participants for whom time and/or physical location would have been barriers. Internet and phone access needed.
- **Where?**
  Remote; phone and internet-based.
- **How?**
  Participant receives survey link and records responses. Active interviewer support via phone/internet, with increased support when participant has no internet.
- **When?** All hours.

Consent and Confidentiality

Initial Implementation Plan

- Surveys conducted in private space
- Introductory script familiarizes participant with survey purpose and process
- Consent process provides information on rights as a research participant.
  - "Do you give your consent to begin the survey?"

Emergency/Disaster (COVID-19)

- Interviewers perform their work in private spaces. They also encourage participants to find a private space for taking the survey.
- Modifications to introductory and consent scripts facilitate participant comprehension and flow through the remote verbal consent process.

Resource Referral Sheets

Development of Referral Sheets

- Individual sheets for each participating county in the Baltimore EMA
- Drafted by workgroup leads and health department staff
- Reviewed, edited, and updated by individuals at partner organizations knowledgeable about high-quality resources in their communities

Administration of Referral Sheets

- Administered to participant at conclusion of survey to provide resources in their county(ies) of residence
  - HIV and STI testing/care
  - Shelter, housing, food, employment, legal aid
  - Health care and health insurance resources
- Administered electronically or as physical sheet in tandem with participant incentive

Incentives

Development of Incentives Protocol

- A range of vendors (5) were selected to provide participants across the EMA with options that would be accessible to them.
- Partner organizations were polled on which vendors would be of value to their clients.

Administration of Incentives Protocol

- Incentive distribution process initiated at conclusion of survey and completed by designated gift card disbursement staff member.
- Disbursement via email, mail, or curbside pick-up (participant preference).
- All contact information kept separate from survey data at all times - *only a fiscal mechanism required by BCHD*.

Interviewer Recruitment

- **Guiding principles**
  - Hiring from the communities engaged as survey participants
    - Interviewers from Baltimore EMA
  - Emphasis on life, volunteer, and work experiences over educational attainment
- **Job posting**
  - Advertised through partner organizations and their networks by word of mouth and flyers (print and digital)
  - Social media
- **Job application**: Survey Monkey
- **Job interviews**
  - In-person and remote options
  - Interview panel of Survey Design and Implementation workgroup members
  - Standardized set of interview questions and scoring system
- **Hiring through Baltimore City Health Department**
  - BCHD: RW Part A, CDC Prevention - Grant Recipient

Interviewer Training

- Format: Multi-day, remote training developed and facilitated by collaborative group of survey planners, local experts, as well as State and City HDs
- Guiding concepts for engagement with participants
  - Cultural humility
  - Research ethics and participant confidentiality
  - Trauma-informed approach
- Interactive, simulation-based training in survey administration protocols, with accompanying Interviewer Training Manual
  - Survey tool administration: questions and flow
  - Resource resource referral sheets and incentives
  - Tablet training and troubleshooting

Status at Time of Submission

- **Completed/Approved - July 2, 2020**:
  - Design and implementation tools and protocols
    - With pandemic-informed modifications
  - MDH IRB approval
    - With pandemic-informed modifications
  - Pre-testing of assessment tool
  - Acquisition of participant incentives
- **Submitted/Underway - July 2, 2020**:
  - Request to acquire LTE-enabled tablets, phone for survey staff
  - Request to hire for interviewers and research manager
    - Goal: August-September
  - Training and onboarding of survey staff
    - Goal: August-September

** Participant recruitment and data collection will not start until staff hired/trained and IT resources acquired.

Final Thoughts & Lessons Learned

- **Survey Design**
  - Flexibility
  - Importance of Data
  - Parking Lot

- **Survey Implementation**
  - Feasibility of remote interviews
  - Parking Lot

Questions? Comments? Shared Experiences?

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