

# Strategies and Lessons Learned for Consumer and Stakeholder Engagement in Integrated HIV Prevention and Care Planning and Implementation

Tuesday July 25, 2017

3:00 p.m. – 4:00 p.m. EDT



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# Webinar Objectives

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**Following the webinar, participants will be able to:**

- 1.** Discuss the importance and benefits of broad consumer and stakeholder engagement for Integrated HIV Prevention and Care Plan development, implementation, and monitoring
- 2.** Identify strategies and methodologies from effective engagement processes for consumer involvement in integrated HIV prevention and care planning.
- 3.** Highlight successes and lessons learned in consumer and stakeholder engagement from Washington, DC and the state of Pennsylvania.



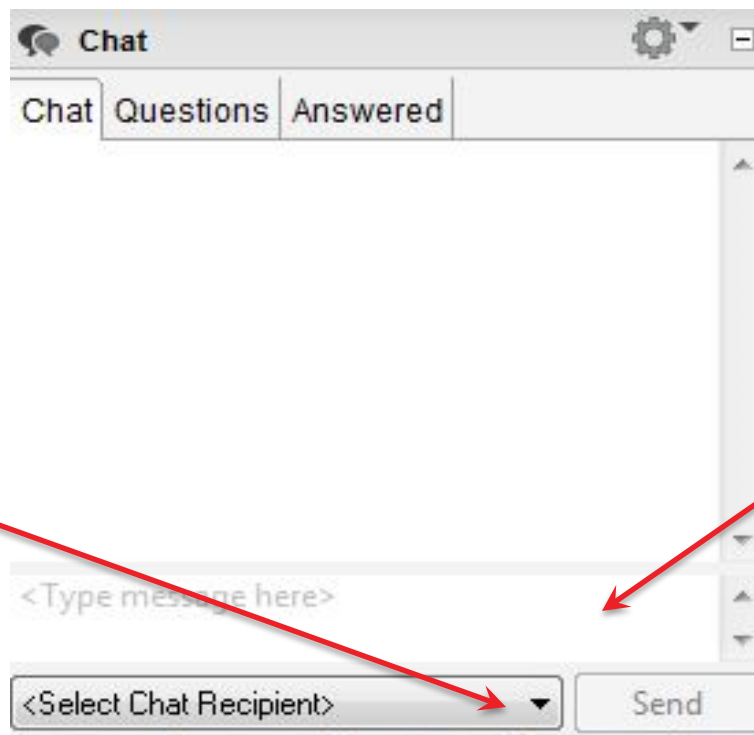
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# Chat Feature

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If you have questions during the call, please use the chat feature. To do so:

Use the drop down arrow to send your comments and/or questions to “Broadcast to All”



Chat comments and/or questions here, and please indicate which jurisdiction you're from.

# About the IHAP TAC

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**3-year  
project**

began  
July 1, 2016

**Supports  
Ryan White  
HIV/AIDS  
Program  
Parts A & B**

grant recipients  
and their planning  
bodies

**Conducts  
national &  
targeted  
technical**

assistance activities



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# Today's Presenters

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**MARISSA TONELLI**  
HealthHIV



**DAVID LYLE GIVENS**  
University of Pittsburgh



**DR. LEAH VARGA**  
Government of the District of  
Columbia  
Department of Health  
HIV/AIDS, Hepatitis, STD and TB  
Administration (HAHSTA)

# Welcome



**STEVEN R. YOUNG, MSPH**

Director, Division of Metropolitan  
HIV/AIDS Programs  
HIV/AIDS Bureau, HRSA

# Overview of Stakeholder and Community Engagement Process

Marissa Tonelli  
HealthHIV



HealthHIV  
Putting Health First

# What is a “Stakeholder” in HIV Planning?

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- **HRSA language:** “The foundation for [planning] is...the key players or ‘stakeholders’ who should be involved...Stakeholders outside of the organization -- patients, funders, patient advocates...”
- **CDC language:** “A person or representative who has personal or professional experience, skills, or expertise in HIV.”
- An essential ‘stakeholder’ group in HIV planning is consumers, people living with HIV (PLWH)



# Defining “Consumer”

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- Consumers are PLWH who receive Ryan White HIV/AIDS Program (RWHAP)-funded core and/or support services (or their caretakers)
- “Unaligned consumers” are PLWH who receive services from a RWHAP Part A provider and do not have a financial or governance interest



# Defining “Consumer”

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- Definitions can be confusing when PLWH receive most medical-related services through public or private insurance or if RWHAP Part B pays insurance premiums and cost-sharing
- Some integrated prevention/care bodies are seeking a new definition for consumers of *prevention* services



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# Legislative Requirements for Consumer Involvement

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- Planning councils must “**reflect in its composition the demographics of the population of individuals with HIV**” in the eligible area, **with particular consideration given to** disproportionately affected and historically underserved groups”
- **No less than 33% of the Council** to be “unaligned” consumers (Section 2602)



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# Benefits of Stakeholder and Community Engagement

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- Provides outcomes that meet the needs of the community
- Ensures HIV services are delivered in collaboration with community stakeholders
- Increases responsiveness and effectiveness of HIV service delivery
- Results in streamlined policy and program development
- Encourages open and transparent lines of communication



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# Benefits of Stakeholder and Community Engagement

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- Drives innovation
- Results in integrated, comprehensive planning
- Creates continued engagement in integrated planning process
- Facilitates bi-directional feedback mechanisms between stakeholder groups to planning bodies, recipients, state/county legislature, government agencies, and others
- Enhances investment in coordinated response to address HIV within jurisdictions

# Consumers (PLWH) are Important Stakeholders

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- Consumer involvement in HIV planning councils and planning bodies ensures that the affected communities are involved in determining service needs, opportunities, and barriers, and how best to address them



# Consumers (PLWH) are Important Stakeholders

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- Consumers involvement at all levels of the planning process, including:
  - Engagement within planning bodies and broader stakeholder engagement activities
  - Developing and monitoring of the Integrated HIV Prevention and Care Plan to ensure culturally competent systems of care



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# Identifying Stakeholders in your Jurisdiction

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- Focus on representatives of populations with high prevalence of HIV infection (i.e. impacted communities) in your jurisdiction
  - Geographic Distribution
  - HIV Risk Categories
  - Race and Ethnicity
  - Gender and Gender Identity
  - Age



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# Poll: Who have you engaged?

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Who are some of the non-traditional HIV stakeholders your jurisdiction has engaged in your Integrated HIV Prevention and Care Plan activities?

- Health Care Centers
- Local Business Owners
- Community Centers
- YMCA/ YWCA
- Philanthropic Community
- Homeless Shelters
- Fraternities/ Sororities
- Foundations
- High-school Student
- School Health Centers
- Primary Care Associations
- Teen Groups (i.e. Young Mothers)
- Other State Agencies
- Social service organizations
- Government
- Other (type into chat box)

# **Stakeholder and Community Engagement Process: Model Strategies**



# Effective Engagement Methods

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- Town hall meetings or other well-publicized public meetings
- Focus groups (at shelters, correctional facilities, faith institutions, community centers, support groups, etc.)
- Survey dissemination
- Key informant interviews
- Public comment period
- Use of social media to drive discussion
- Advanced technology, such as webinars or conference calls
- Community advisory boards
- Ad hoc panels voting and non-voting members of planning bodies
- Advisory groups to HIV planning bodies

# Engagement in Plan Development, Implementation, and Monitoring

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- Inform development of an Integrated HIV Prevention and Care Plan and monitor implementation and improvement, including outcomes of key strategies and activities.
- It is essential to ensure *continuous, ongoing* stakeholder engagement in planning implementation and monitoring via:
  - Development of effective feedback loops
  - Evaluation and demonstration of outcomes and value of stakeholder engagement efforts
    - Sharing how planning bodies are using information gathered during engagements with community stakeholders

# Engagement in Plan Implementation and Monitoring

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- In order to monitor Plan implementation, access is needed to timely information, including:
  - Evaluation criteria/metrics
  - New programs/program goals and measures
  - Recent and upcoming activities
  - Up-to-date epidemiological data.
- Continued research and development is needed on user-friendly tools to enhance community-based monitoring of the integrated HIV plan implementation

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MARYLAND



# Maryland Engagement

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- To engage a broader community in the Integrated HIV Prevention and Care Plan development process, Maryland's planning body sought feedback from advisory groups, including:
  - Five Regional Advisory Committees, the Baltimore Planning Council, the Anne Arundel Commission, and the Baltimore City Commission
  - MSM Response Team
  - Transgender Response Team
  - HIV Perinatal Team
  - Maryland Hepatitis Coalition
  - STI Community Coalition



WASHINGTON



# Washington Engagement

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- Formal planning group focuses on frameworks, strategies, and systems.
- The Community Engagement program (i.e. “stakeholder villages”) are its avenues for input and exchange.
  - Purpose: Take engagement beyond the confines of the planning group table.
    - Barbershops
    - Interactions between clients and DIS staff
    - Client survey
    - Social media
    - Going to communities and actively soliciting input on specific questions

A yellow silhouette of the state of Georgia is centered on a dark gray background. A red dot is placed in the northern part of the state, to the left of the word "ATLANTA". A solid red horizontal line spans the width of the image, passing behind the map.

● ATLANTA

# Fulton County, Georgia

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- Fulton County (Atlanta, GA) and the state of Georgia convened several half-day and day-long community engagement meetings for community members over the course of a year that identified and prioritized innovative HIV prevention, care, and treatment strategies and elicited feedback on HIV planning goals.

# Meaningful Stakeholder/Consumer Engagement Must....

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- Occur regularly
- Consult a range of impacted stakeholders
- Occur in a variety of venues and formats, accommodate the needs and preferences of community members
- Challenge conventional wisdom and encourage innovation
- Occasionally take us out of our comfort zone

# Consumer and Stakeholder Engagement in Pennsylvania's Integrated HIV Prevention and Care Plan

**David Givens**

Director, HIV Prevention and Care Project

Graduate School of Public Health, University of Pittsburgh



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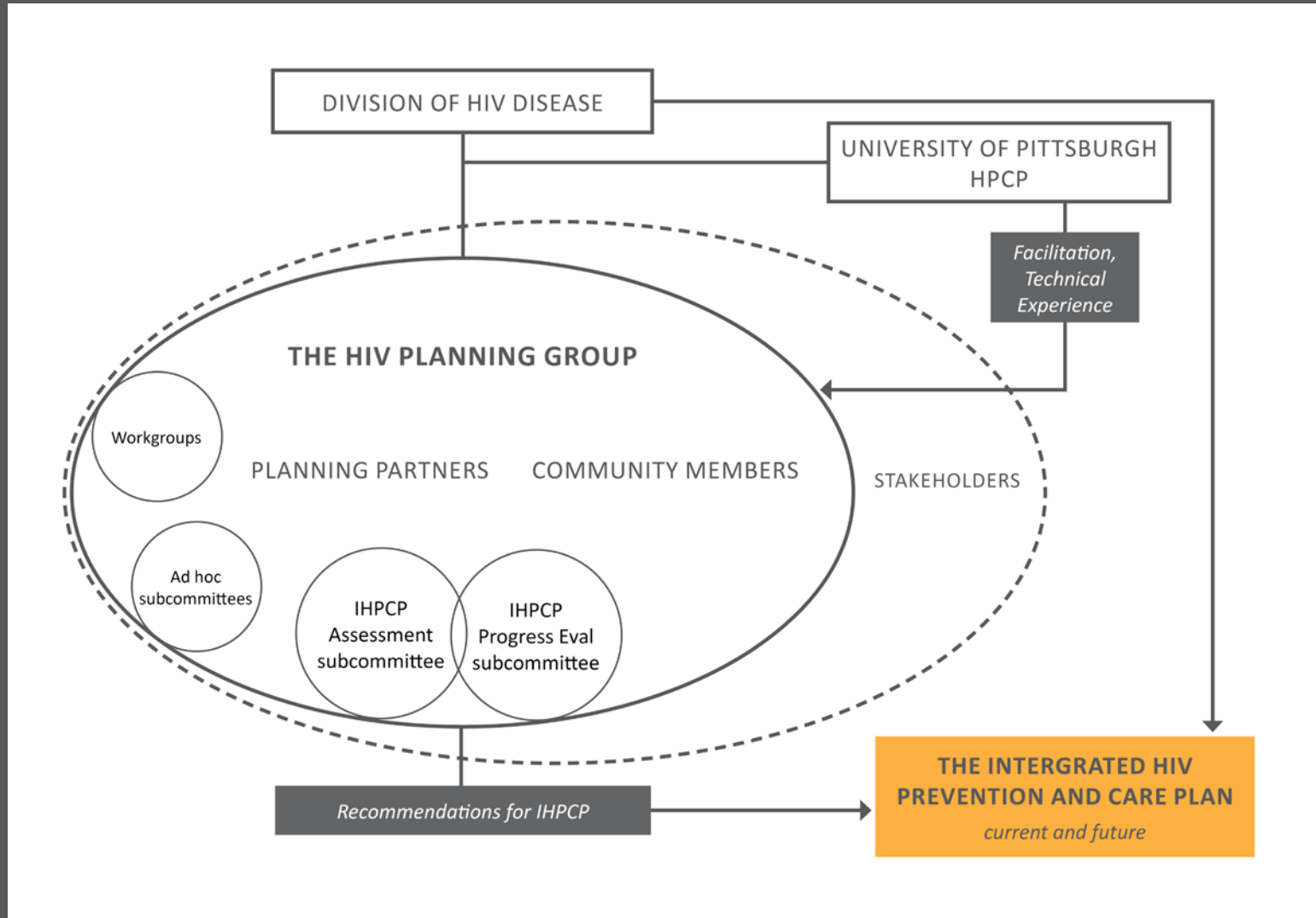
# Introduction

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- The PA Integrated HIV Prevention and Care Plan (IHPCP) includes multiple subsections on stakeholder and PLWH engagement
- The PA HIV Planning Group (HPG) used the integrated planning process to develop a robust method for engaging stakeholders
- These efforts informed the IHPCP contents



# Composition of the HPG in Pennsylvania





# Mechanics of PA Stakeholder Engagement

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The 5-year stakeholder engagement cycle:

- Identify gaps and underrepresented groups from the IHPCP and HPG
- Targeted subpopulation group/organization outreach
- Town halls and focus groups
- Survey and/or IHPCP feedback
- Analysis and integration into the IHPCP

# ID Gaps and Underrepresented Groups

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Concept: Identify high-risk/highly impacted groups underrepresented at the HPG and/or in the IHPCP

Examples:

- Needs assessments for: linking rural HIV positive individuals to care; prevention efforts in disability communities
- Surveying direct service providers regarding cultural competency for transgender clients

# Targeted Subpopulation Group/Organized Outreach

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Concept: Once underrepresented groups are identified, how do we reach them?

Examples:

- Panel sessions at the HPG on community needs and perspectives
- Recommended expansion of successful state project targeting at-risk black MSM and trans youth (Project SILK)
- In-person and virtual outreach to target communities

# Town Halls and Focus Groups

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Concept: Provide direct opportunities for consumers and providers to have their voices heard.

Examples:

- Town halls in multiple locations across the state to engage HIV positive individuals and discuss barriers and facilitators for retention in HIV care
- Focus groups:
  - Black MSM and trans youth
  - LGBTQ exp. with stigma

# Survey: Integrated HIV Prevention and Care Plan Feedback

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Concept: Solicit feedback on draft IHPCP goals, contents, and issues through surveying

Example:

- IHPCP survey with wide distribution patterns over multiple media formats
  - Received almost 1,000 surveys (paper and electronic) and 223 free-response comments
  - Multiple benefits for electronic survey formatting

# Analysis and Incorporation

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- Interpret, summarize, incorporate information
- Capitalize on engaged stakeholders from this process
- Provide stakeholders with feedback
- Identify underrepresented groups

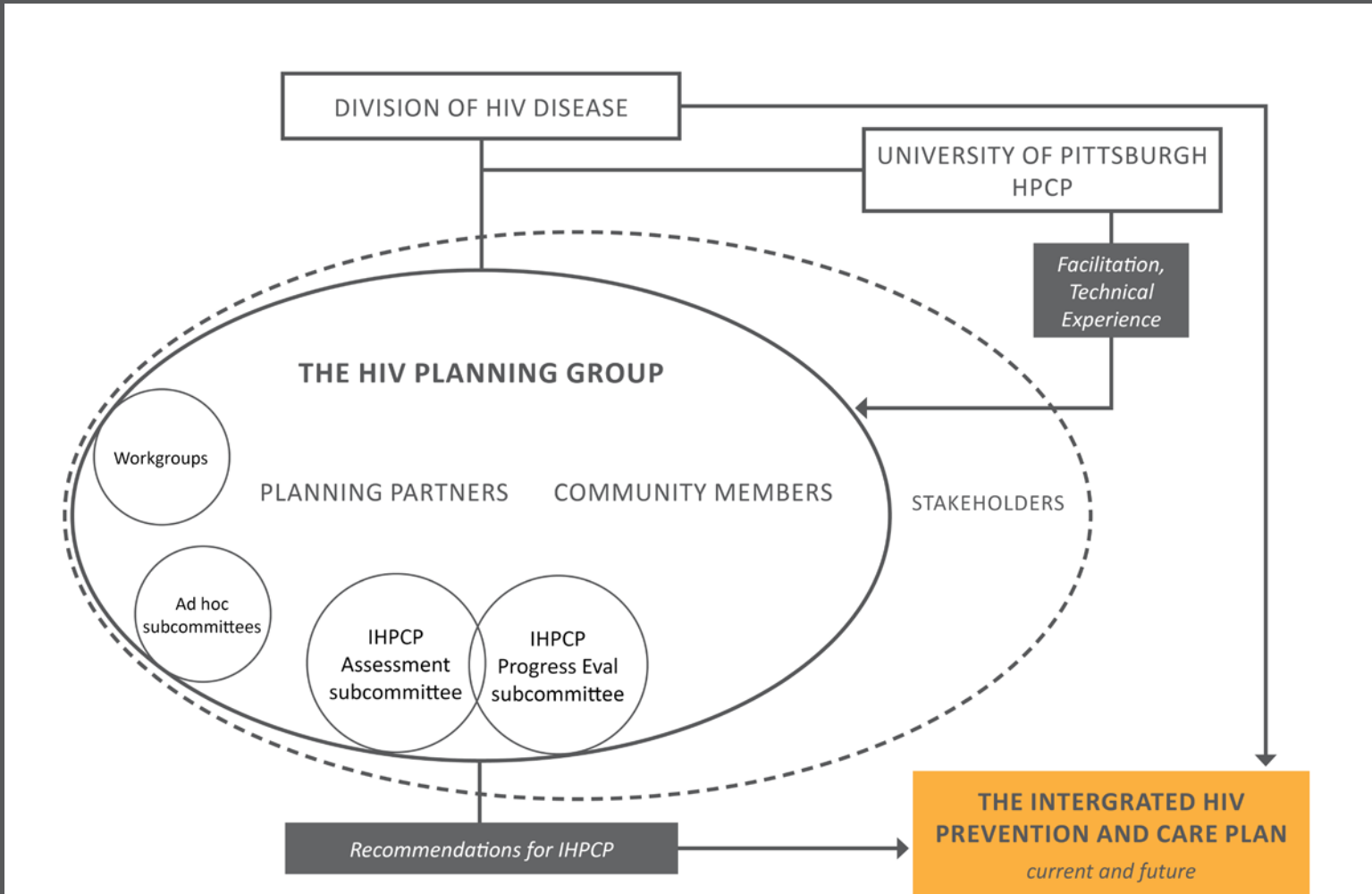
# Monitoring and Improvement

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- Implementation components built into the Integrated HIV Prevention and Care Plan
- Stakeholder roles:
  - HPG toolkit in place for monitoring and evaluation recommendations
  - Ability of HPG Stakeholder engagement processes to synchronize with ongoing assessment

# Monitoring and Improvement

- HPG Monitoring and Evaluation toolkit



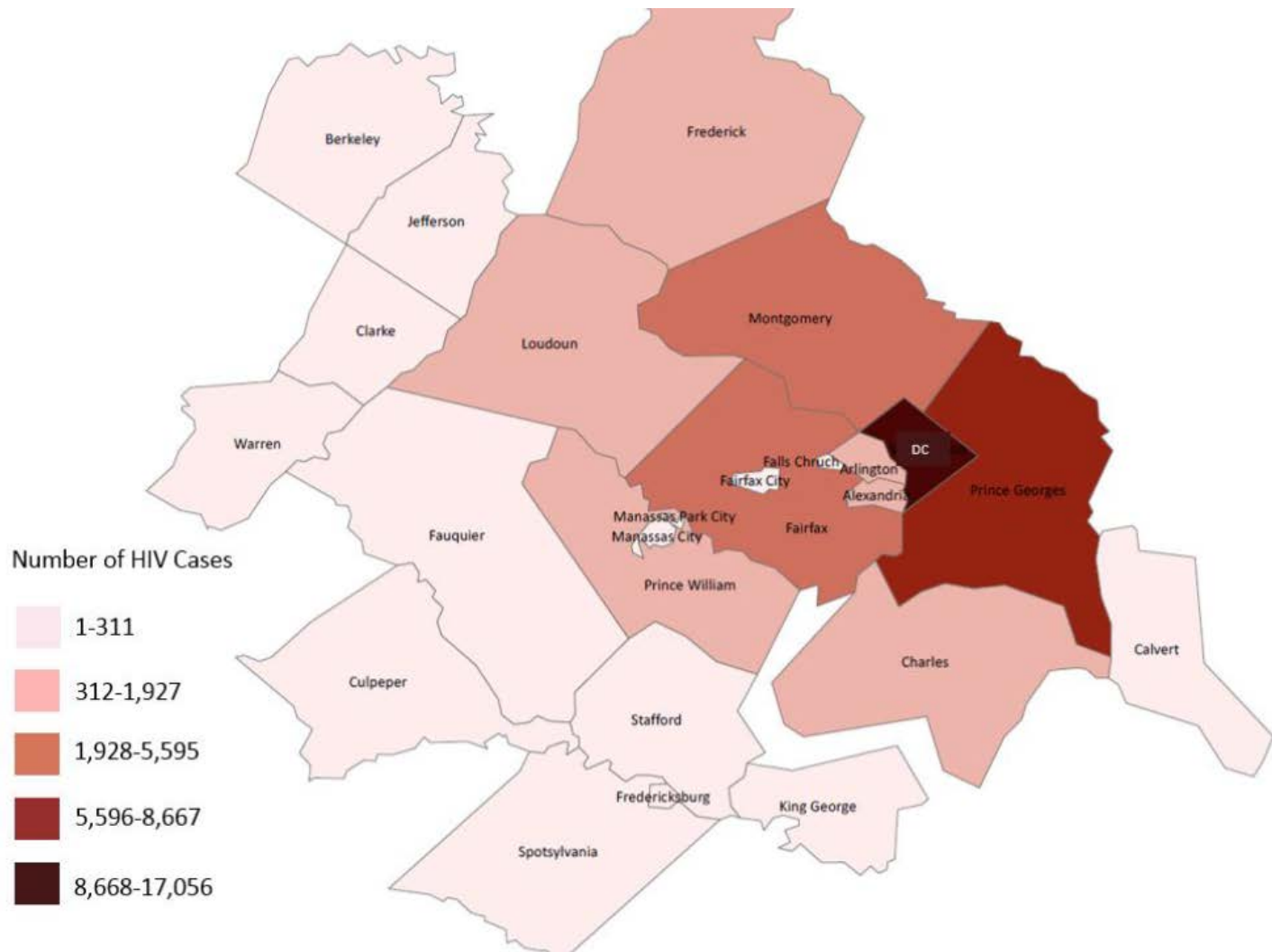


# Consumer Engagement in HIV Integrated Planning in Washington, DC

**Dr. Leah Varga**

Government of the District of Columbia, Department of Health,  
HIV/AIDS, Hepatitis, STD and TB Administration (HAHSTA)

# Geographic Distribution of the Number of People Diagnosed and Living in the Washington DC EMA, by County, 2015, N=36,717



# Integrated Planning

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## Goals to End the Epidemic

- **Goal 1:** Reducing New HIV Infections
- **Goal 2:** Increasing Access to Care and Improving Health Outcomes for People Living with HIV
- **Goal 3:** Reducing HIV-related Disparities and Health Inequities
- **Goal 4:** Achieving a More Coordinated National Response



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# Integrated Planning

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## 90/90/90/50

- 90% of DC residents living with HIV know their status
- 90% of DC residents diagnosed with HIV are in treatment
- 90% of DC residents living with HIV who are in treatment reach viral load suppression
- 50% reduction in new HIV infections



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# Community and Stakeholder Engagement

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- Leveraging existing relationships
- EMA wide learning experience
- Thinking “regionally”
- Community Engagement not a “rubber stamp” or checking a box



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# Collaborations, Partnerships, and Stakeholder Involvement

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- Mayor's Plan
- Local/State Health Departments
- Academic partnerships



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# Community Engagement and Input

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- What do we mean by “community”?
  - People living with HIV
  - At-risk groups
  - Representatives of various genders, sexual orientations, races, ethnicities, ages, countries of origin reflecting experiences and expertise of those impacted by HIV



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# Community Engagement and Input

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- Needs Assessments
- Town Halls
- Patient Satisfaction
- Planning Bodies
  - Workgroups
  - PSRA Process



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# Integrated HIV Prevention and Care Plan Workgroup

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## HIV Prevention and Planning Group

- Community-based organizations serving affected populations and AIDS service organizations
- Academic/research institutions
- Affected communities, including people living with HIV, members of a Federally recognized Indian tribe as represented in the population, individuals co-infected with hepatitis B or C, and historically underserved groups and subpopulations

# Integrated HIV Prevention and Care Plan Workgroup

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## Metropolitan Washington Regional RWHAP Planning Council

- Community-based organizations serving affected populations and AIDS service organizations
- Affected communities
- State government (including the State Medicaid agency and the agency administering the program under Part B).
- Representatives of individuals who formerly were Federal, State, or local prisoners, were released from the custody of the penal system during the preceding 3 years, and had HIV as of the date on which the individuals were so released

# Challenges and Lessons Learned

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- Aligning the various local and regional plans
- Standardization across jurisdictions
- Keeping up with what is going on in the community (and listening!)
- Engaging emerging and underrepresented populations
- Community involvement burden



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# Remaining Engaged

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- Integration “task force”
- Monitoring
- Improvement
- Plan workgroups
- Standing agenda item at Planning Body meetings
- Expanding technology



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# Community Outreach

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- Press releases
- Town Halls/Twitter Town Halls
- Podcasts
- Peers and Health Impact Specialists
- Data to Care
- Ethnographic Work



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# Questions

Please chat your questions into the Chat Box.



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# Thank you!



**STEWART**



**JULI**



**JULIE**

**Please complete the webinar evaluation.**

Contact the IHAP TAC at [ihaptac@jsi.com](mailto:ihaptac@jsi.com) to obtain more information, join our mailing list, or to share your experience.

This project is supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) under grant number U69HA30144, Ryan White HIV/AIDS Program Integrated HIV Planning Implementation. This information or content and conclusions are those of the author and should not be construed as the official position or policy of, nor should any endorsements be inferred by HRSA, HHS or the U.S. Government.