

**Final Report: HIV/AIDS Strategy
Stakeholder Engagement Meetings, 2012-2014**

Illinois HIV Planning Group

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Acknowledgements

The Illinois HIV Planning Group (ILHPG) wishes to thank everyone who contributed to the successful completion of the HIV stakeholder engagement meetings in 2014 and throughout the three-year cycle of regional meetings. In particular, we want to recognize the members of the Evaluation Committee, the workgroup that helped to create the protocol, discussion guide, and evaluation plan for these meetings, the regional lead agents and ILHPG members who helped develop broad regional stakeholder invitation lists, Illinois Department of Public Health (Department) HIV Section staff who developed meeting materials and presentations for the meetings, and engagement meeting facilitators, recorders, and participants.

Looking back at the initial thought, planning, and final decision to conduct this series of regional engagement meetings, I want to say how proud the Illinois HIV Planning Group and the Department should be of this tremendous accomplishment. The protocol and the discussion questions that were developed for these meetings were crafted with a keen vision of what was needed to achieve the National HIV/AIDS Strategy (NHAS) goals and to develop an HIV care and prevention plan for the state that aligned with those goals. The responses we received and the analyses have been and will continue to be used to guide improvements in existing HIV care, prevention, and treatment services as well as new strategies and initiatives. The regional meetings were truly successful in engaging new and existing key community stakeholders in regional and statewide HIV planning. Looking at the bigger picture, these meetings have also become a vehicle to help Illinois achieve a more comprehensive and coordinated response to HIV care and prevention, which will facilitate our achievement of the NHAS goals.

Janet Nuss
Illinois HIV Planning Group Coordinator

Introduction and Overview

This report is the last in a series of three annual reports on HIV stakeholder engagement meetings that the Illinois HIV Planning Group held across the state of Illinois outside the city of Chicago. The HIV/AIDS strategy stakeholder engagement meetings were a component of the Illinois Department of Public Health 2012-2014 HIV Engagement Plans—which align with the Illinois HIV/AIDS Strategy (IHAS) —and are part of a larger effort to increase coordination across HIV care, treatment, and prevention programs. Three regional meetings were held in 2014, two in 2013, and three in 2012, for a total of eight HIV/AIDS strategy stakeholder engagement meetings.

Together, the eight engagement meetings generated a wealth of ideas, many of which the Department and the ILHPG are already using to inform new initiatives and improvements at all levels of HIV prevention, care, and treatment services system in Illinois. We counted on this happening because we knew that the Department and the HIV Planning Group could not rely solely on the federal government to address the needs in our state. And we knew, too, that localities and communities could not rely solely on the State to do so. Finding the solutions that work best for our communities will continue to require that we all work together to address the common challenges that State, regional, and local HIV planners and providers face as they work to meet the needs of people living with HIV and high-risk populations and communities.

Opportunities for change are plentiful. Our hope is that the stakeholder engagement meetings and the accompanying reports will assist stakeholders as they create, implement, and evaluate programs and services and—together—develop a response to HIV in Illinois that prevents new infections, improves health outcomes for people living with HIV, reduces HIV-related health disparities, and combats HIV/AIDS stigma and discrimination. A list of acronyms used throughout this final report is provided for the reader as Appendix A.

Background

In 2010, President Obama released a comprehensive roadmap for addressing the national HIV epidemic called the National HIV/AIDS Strategy. The NHAS prompted several actions in Illinois. In 2011-2012, the Interagency AIDS Task Force (IATF) developed the Illinois HIV/AIDS Strategy, with state-specific goals and objectives aligned with the NHAS. The Illinois HIV Planning Group then responded to the NHAS and the state strategy by developing the first Illinois Department of Public Health HIV Engagement Plan in 2012. The ILHPG has continued to develop engagement plans in subsequent years. These plans identify strategies and activities to enhance coordination across HIV care, treatment, and prevention programs across the jurisdiction. A key component of the engagement plans was conducting HIV/AIDS strategy stakeholder engagement meetings throughout the state. Community stakeholders were brought together to help identify gaps, deficiencies, and barriers in services and to strategize on enhancing collaboration and coordination in HIV program planning, delivery, and evaluation.

In 2014, stakeholder engagement meetings were held in Region Two—Heart of Illinois, Region Five—Southern Illinois, and Region Seven—Collar Counties. The first meetings were held in

2012 in Regions One, Four, and Six (Northwest Illinois, Southwest Illinois, and East Central Illinois), followed by 2013 meetings in Region Three and Region Eight (Central Illinois and Suburban Cook County). The meeting goals were the same for all eight meetings: (1) to increase community stakeholders' awareness and understanding of the national and Illinois HIV/AIDS strategies and how they translate to state and local HIV care, treatment, and prevention programs, and (2) to achieve a more coordinated response to the HIV epidemic by engaging community stakeholders and enhancing collaboration and coordination among HIV programs.

The Planners and Participants

Plans for the stakeholder meetings were developed initially by an engagement meeting workgroup. The workgroup was formed by the ILHPG Planning Group Evaluation Committee—which was tasked with responsibility for the meetings by the ILHPG Executive Committee—and included members of the Evaluation Committee, two community representatives who were past ILHPG members, the Department's Evaluation Administrator, and the ILHPG Coordinator. The workgroup established the protocol, discussion guide, objectives, and procedures for conducting and evaluating the meetings. Breakout discussions were a key feature of the meetings, with questions designed to elicit ideas and opinions from all participants—a strategy that proved enormously successful over the course of all eight meetings. Working together in the first few months of 2012, the workgroup researched and reviewed sample materials and conceived and developed meeting documents. This protocol was revised in 2013 for the 2013-2014 meetings. For more information about that work, see Appendix B, which is the revised protocol for the HIV/AIDS Strategy Stakeholder Engagement Meetings. It summarizes the process established to plan, conduct, and evaluate the meetings including how to identify and invite participants to ensure a diverse, representative group of attendees at each meeting.

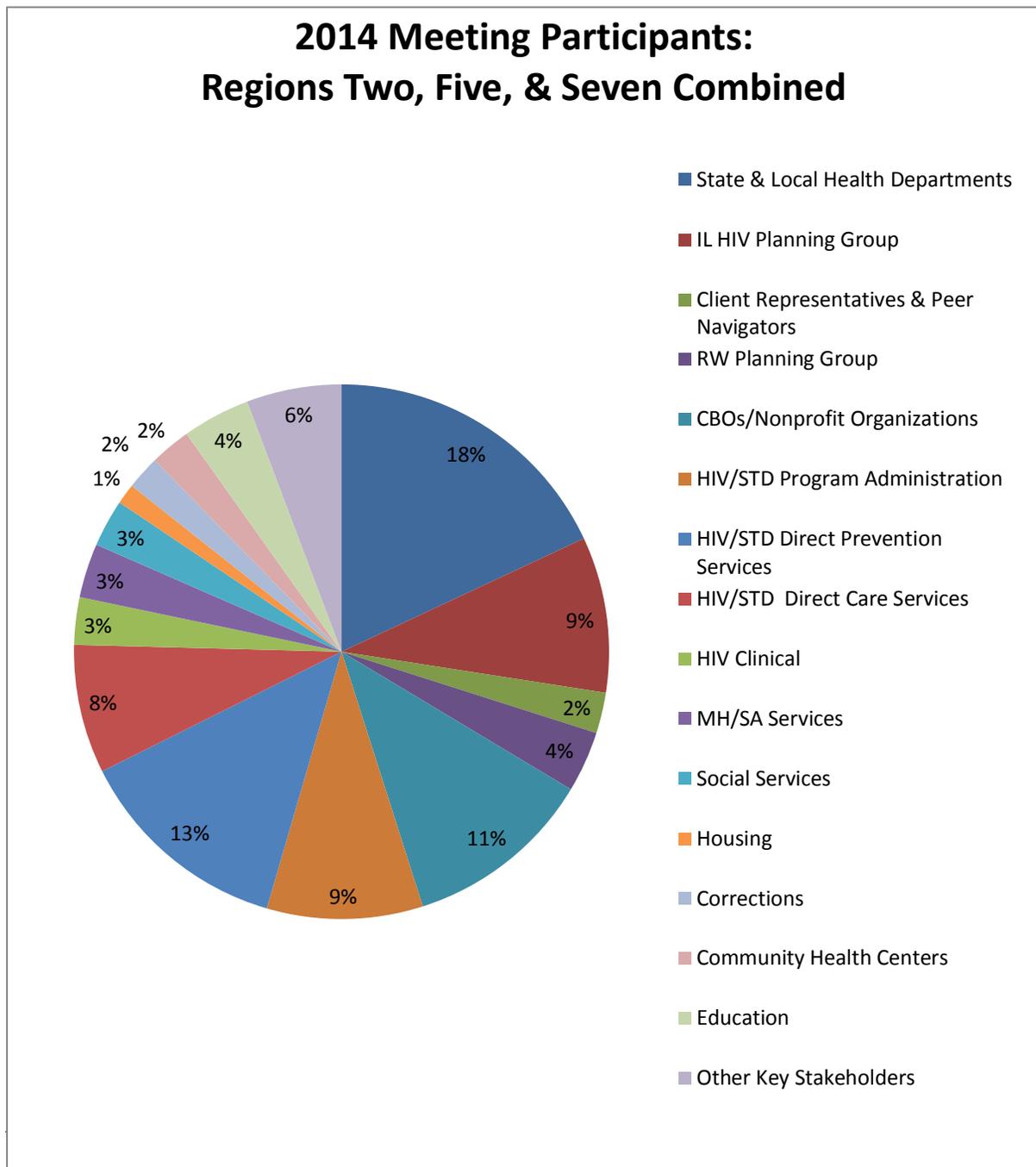
In 2014, the ILHPG Coordinator worked with the HIV care and prevention lead agents from Regions Two, Five, and Seven to identify key stakeholders and develop a comprehensive list of invitees for each meeting. Among the categories of representatives included on the 2014 invitation lists were the following:

- State and local health department HIV and STD programs
- Illinois HIV Planning Group
- Clients and peers
- Ryan White Advisory Group
- Community-based organizations/nonprofit organizations
- HIV and STD program administration
- HIV/STD direct prevention services
- HIV/STD direct care services
- HIV/STD clinical care
- Mental health/substance abuse services
- Social services
- Housing
- Corrections
- Community health centers

- Education
- Other key stakeholders such as other government agencies and faith-based organizations (indicated separately by meeting)

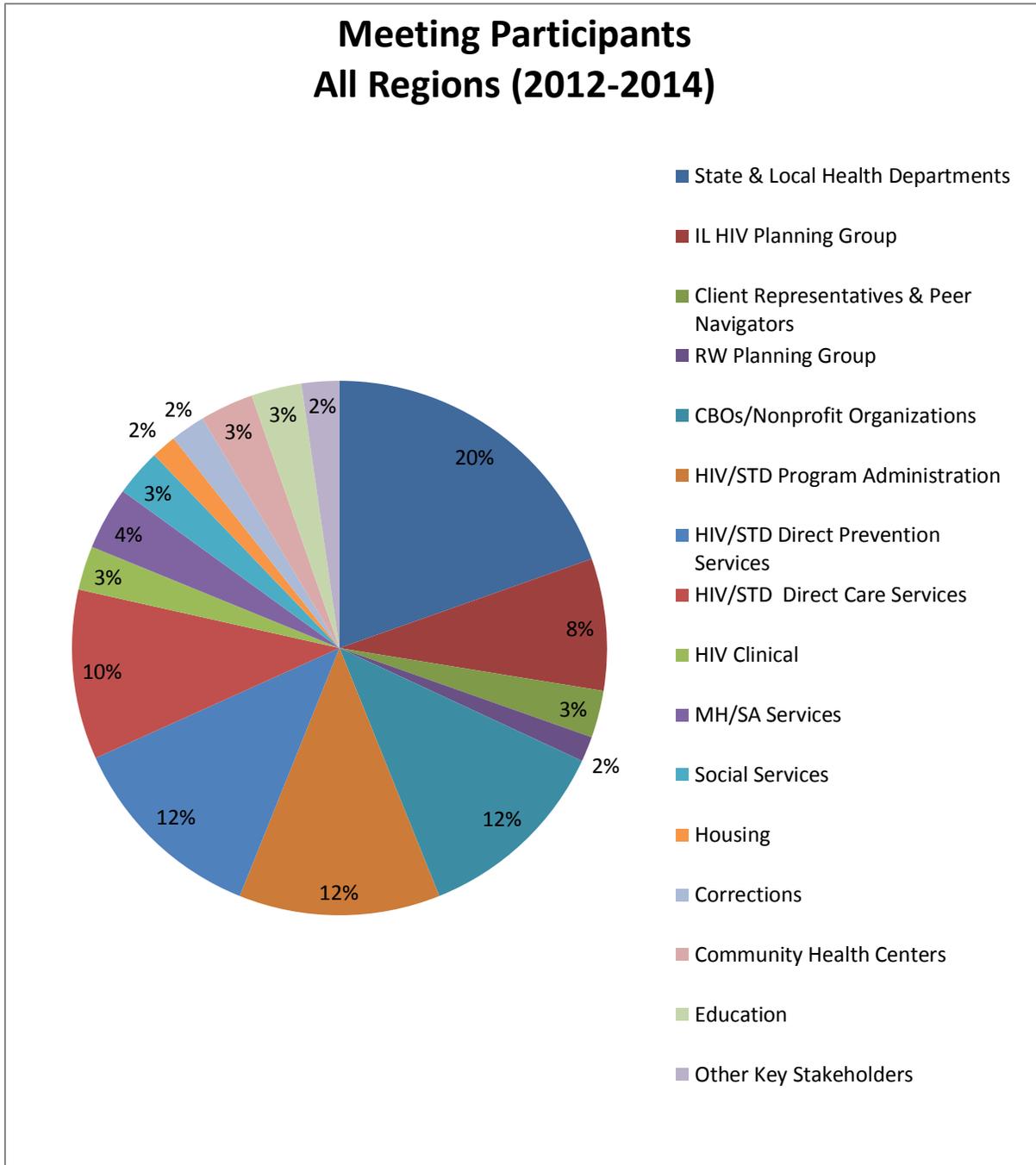
Figure 1 is a combined breakdown of 2014 meeting attendees by category. Figure 2 on the following page provides the same data for all eight meetings combined. Note that categories of invited representatives changed between the 2012 and 2013 meetings to allow for a more detailed picture of who took part in the meetings.

Figure 1



Therefore, the combined graph below provides a general picture of the meeting participants across all three years. (For comparison purposes, Appendix C and D provide a breakdown of 2012 and 2013 meeting participants respectively.)

Figure 2



The three 2014 meetings were well attended. In total, 267 people were invited, and 125 people attended; 32 took part in the Region Two meeting in Peoria, 23 attended the Region Five meeting in Carbondale, and 38 attended the Region Seven meeting in Elmhurst. Stakeholders who were not ILHPG members or Department-funded providers were offered a \$25 gift card to support their transportation costs.

The three-year series of HIV strategy community engagement meetings conducted from 2012 to 2014 has been a successful effort to engage key regional stakeholders in statewide HIV planning. In total, 695 stakeholders were invited to attend one or more of the eight regional meetings, and 307 stakeholders participated.

Meeting Objectives and Questions

Over a period of several weeks early in 2012, the stakeholder engagement meeting workgroup developed meeting objectives, breakout discussion group questions, and a discussion guide (See Appendix E). Throughout their work, the group kept two desires in mind. They wanted meeting participants to enjoy the meeting and have an opportunity to be heard, and they wanted the meetings to generate the most and best information and insights for use in state and regional program planning. Judging by the meeting evaluations and the quality and volume of information gathered across the eight regions, both of these aspirations were met.

The Objectives

Five objectives—each aligned with a goal of the national and Illinois HIV/AIDS strategies—were developed as the foundation for the stakeholder engagement meetings.

- Objective 1: To engage local health departments, other HIV programs (care, treatment, and prevention), and other key stakeholders in HIV planning.
- Objective 2: To identify opportunities for collaboration and coordination across all HIV programs, statewide and local.
- Objective 3: To develop strategies to reduce new HIV infections and reduce HIV-related disparities and health inequities.
- Objective 4: To increase linkage and access to care and improve health outcomes for people living with HIV.
- Objective 5: To identify ways to mitigate the impact of stigma and discrimination on HIV care, treatment, and prevention.

The Questions

Once the objectives were developed, the workgroup crafted questions for each objective designed to focus the breakout group discussions and help the groups stay on target. The questions were carefully designed to be open-ended, to address the meeting objectives, and to be capable of qualitative analysis. To keep the discussions moving and to make sure that all groups considered every question, the workgroup assigned time limits for each question. Four of the five questions included an introductory statement linking the question back to the Illinois strategy:

- Question 1: The strategy impels us to engage entities from HIV prevention, care, and treatment; STD, TB, and viral hepatitis; mental health and substance use; housing; related supportive services; and other key stakeholders in HIV planning.
 - 1.1 What other entities need to be engaged in this process and at what level (referral, planning) should they be engaged?
 - 1.2 What would you like to see come out of these planning efforts?

- Question 2: The strategy impels us to increase coordination and collaboration across HIV prevention, care, and treatment; STD, TB, and viral hepatitis services; mental health and substance use services; housing and other supportive services.
 - 2.1 What potential opportunities for collaboration and coordination of activities do you see?
 - 2.2 What are the challenges or barriers to this?

- Question 3: The strategy says three critical steps we must take to reduce HIV infection are: (1) intensify prevention efforts in communities where HIV is most heavily concentrated; (2) expand targeted efforts to prevent infections using a combination of effective, evidence-based approaches; and (3) educate all Americans about the threat of HIV and how to prevent it.
 - 3.1 How do we balance the demand to intensify targeted interventions for the most impacted populations and the need to provide general education and prevention services?
 - 3.2 Federal and State HIV prevention funds for Illinois were cut this year and may be cut in future years. Knowing that, what recommendations can you provide the State about ways to best intensify prevention efforts in communities where HIV is most concentrated?
 - 3.3 What HIV health inequities do you see and what strategies can you suggest to address them?

- Question 4: Comprehensive prevention services (including partner services) for persons living with HIV are a priority of the strategy.
 - 4.1 What needs to be done to ensure HIV-positive individuals have access to prevention, care, treatment, and supportive services to decrease the risk of HIV transmission to their partners and retain them in care?
 - 4.2 What does your organization need to incorporate prevention for HIV positives into its array of services?
 - 4.3 What are some challenges or barriers your organizations face in providing comprehensive prevention for positives services?

- Question 5—Note that questions 5.1 and 5.2 were prefaced by an epidemiological profile summary of the epidemic specific to the region for each meeting.
 - 5.1: What does your organization need to implement effective, appropriate interventions for this population?
 - 5.2 What needs to be done at the structural level (policies, laws, and infrastructure) to reduce stigma and to ensure clients have access to services that are culturally appropriate?

Meeting Agenda

The HIV/AIDS strategy stakeholder engagement meetings were five to six hour events that included presentations on the National HIV/AIDS Strategy, the Illinois HIV/AIDS Strategy, the Department's HIV Engagement Plan, and the epidemic specific to each region. The meeting agenda template outlines the content, presenters, and breakout group discussions by timeframe (see Appendix F for the 2014 template).

To get the most out of each meeting, the content and the meeting flow were carefully coordinated and facilitated. Each meeting opened with a welcome to participants and a meeting overview. The facilitator explained the protocol and discussion guide to establish ground rules for the group, make participants comfortable with their level of knowledge about the HIV/AIDS strategies, and spark their interest in voicing their opinions and concerns during the breakout group discussions. Then, there were presentations on the National and Illinois HIV AIDS Strategies and the HIV epidemic specific to the host region. Mapping of the region demonstrating the geographic distribution of HIV incidence and prevalence was provided and reviewed with attendees. Following the presentations, time was available for questions and answers before proceeding with the breakout group discussions. The meetings closed with small group reports back to the larger group.

2014 Breakout Group Discussions

The breakout discussion groups were at the core of the stakeholder engagement meetings. Presentations on the NHAS and IHAS, the Department's 2014 HIV Engagement Plan, and the epidemic in the region primed the discussions. Regional maps showing HIV incidence and prevalence by race/ethnicity and risk groups were a meeting resource much appreciated by participants.

With guidance from carefully chosen and well-prepared breakout group facilitators, the lively discussions covered every question, and, for later comparison purposes across groups, the facilitators ensured that each question was discussed as written. The meeting facilitator moved among the breakout groups, answering questions, monitoring time, and helping focus participants. Assigned note takers recorded comments that were summarized in a report out to participants at the end of the breakout session. These notes are the primary source for this report. For a compilation of the meeting notes from Regions Two, Five, and Seven, see Appendix G.

As was true in 2012 and 2013, the 2014 breakout group discussions yielded a rich vein of information and ideas arising from the experiences and perspectives of the participants. The process for analyzing the 2014 data arose from what we learned following the 2012 engagement meetings. For those meetings, we initially had focused on looking for differences among the regions. We had assigned each response to one of four categories—economic, psychological, social, and structural—and developed charts and tables showing the breakdown of responses by type and region. Contrary to our expectations, though, our analysis did not show significant regional differences in responses. When we dug deeper into the data, we also realized that our categories were not a good match for the complexity and richness of the responses. In the end, we went with a more descriptive analysis that was better suited to yielding usable information for

stakeholders—focusing on common threads across the regions. We used that same approach in 2013 and again this year.

The next section of this report summarizes the discussion results separately for Regions Two, Five, and Seven, and then highlights the common threads.

2014 Meeting Results

The following meeting summaries detail responses to the meeting questions generated by the breakout discussion groups. To ensure that everyone had a chance to be heard, participants in the Region Two and Region Seven meetings were divided into smaller discussion groups—four groups for Region Two and six for Region Eight.

Please note that although space constraints do not permit the inclusion of every response in the summaries, every comment, idea, and suggestion in the complete meeting notes has been reviewed by leadership of the Department’s HIV Section and the ILHPG. In fact, they are already being used—along with the contributions from the first five regional meetings—to inform the work of the Department and the HIV Planning Group.

The Region Two—Heart of Illinois Meeting

The Region Two stakeholder engagement meeting was held on May 9, 2014 at the Peoria Main Library. Ninety-eight people were invited; 32 attended. Figure 3 on the following page shows participant affiliations by category.

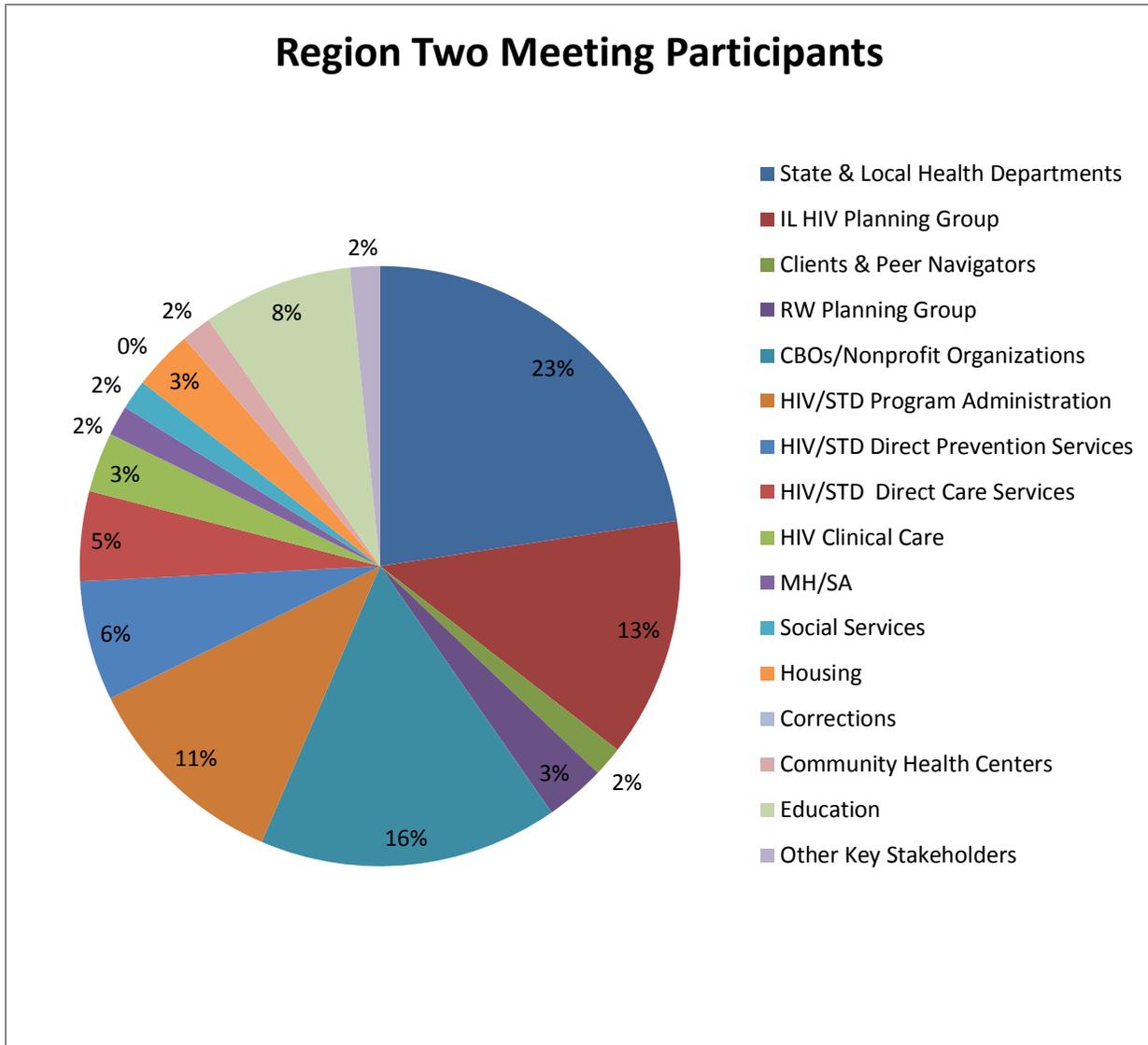
About Region Two

Region Two—Heart of Illinois includes the following counties: Fulton, Hancock, Henderson, Knox, LaSalle, Marshall, Mason, McDonough, McLean, Peoria, Putnam, Stark, Tazewell, Warren, and Woodford. The Region Two care lead agent is the University of Illinois College of Medicine Peoria Heart of Illinois HIV/AIDS Center, and the prevention lead agent is the Illinois Public Health Association. For more information, see Region Two: Heart of Illinois HIV Care Connect, <http://www.hivcareconnect.com/heartofillinois.html>.

From 2008 to 2012, the number of new HIV diagnoses in Region Two decreased at a greater rate (25 percent) than new cases diagnosed statewide (6 percent). There was an average of 37 new HIV diagnoses in this Region each year during that period. Males represented 80 percent of all new HIV diagnoses in Region Two from 2008 to 2012. Women represented just 20 percent of new diagnoses during that period, and 84 percent of those diagnoses were attributed to heterosexual contact. There were 69 percent fewer diagnoses among women in 2012 compared to 2008. Blacks made up 35 percent of new cases in 2008; in 2012, they accounted for 60 percent. Overall blacks and whites accounted for nearly equal proportions of all new cases diagnosed between 2008 and 2012 (45 percent for each group). Among men who have sex with men (MSM), whites accounted for slightly over half of all new HIV infections diagnosed among MSM between 2008 and 2012, but there was a sharp increase in the proportion of new infections

among black MSM during that period—rising from 33 percent of new infections among MSM in 2008 to 69 percent of new infections among MSM in 2012.

Figure 3



Discussion Questions and Responses

Question 1: The strategy impels us to engage entities from HIV prevention, care, and treatment; STD, TB, and viral hepatitis; mental health and substance use; housing; related supportive services; and other key stakeholders in HIV planning. (Note: Although the question asked for entities other than those named in the strategy, some responses were so frequent that they are included here and in the other meeting summaries.)

1.1 What other entities need to be engaged in this process and at what level (referral, planning) should they be engaged?

- State agencies serving people in need
- All county health departments
- Local government
Mentioned were city councils, county supervisors, and the Township Relief Office
- Training entities
- United Way, including Heart of Illinois 2-1-1 line
- Mental and behavioral health agencies and providers
- Churches and clergy
Mentioned were African American churches, First Methodist Church
- Cultural groups such as NAACP, Hispanic Caucus, and Hispanic advocacy groups
- Lesbian, bisexual, gay, transgender, and questioning (LGBTQ) support agencies
- Organizations and agencies supporting veterans and their families
- Prairie State Legal Services, which serves low-income, HIV-positive clients
- Housing agencies and providers
- Planned Parenthood and the Reproductive Planning Committee
- Department of Child and Family Services (DCFS)
- Human services agencies
- Vocational rehabilitation
- Law enforcement and the corrections system
Participants mentioned the Department of Corrections, juvenile justice, parole, jails, and prisons including Illinois River Correctional Center and Federal Correctional Institution Pekin.
- Hospital systems, hospitals, medical clinics, Federally Qualified Health Centers (FQHCs), and other health centers
- Medical and nursing system and providers
Mentioned were OB/GYN providers, pediatricians, parish nurses, medical schools and faculty, and residency programs.
- Affordable Care Act (ACA) navigators and other entities signing people up for insurance
- Community colleges, universities; business and marketing students who could conduct projects
- Parents
- Advocates

1.2 What would you like to see come out of these planning efforts?

- Increased community awareness and mobilization, a better educated public about HIV
- Better understanding of the relationship between local and disproportionate HIV rates
- Fewer gaps in care
- Less duplication of services
- Better coordination among the many available services; better working together by stakeholders and more resource sharing

- More action—funded and focused action
- Training for frontline staff
- A listserv for providers to share resources and learn from each other
- A comprehensive referral list and resource guide
- An email list to inform about funding opportunities
- A vehicle for sharing information about events such as Summits of Hope
- Better understanding among agencies about the need for them to engage in HIV planning and how they relate to each other
- Case management system and providers engaged in networking with other systems—prevention, clinical providers, corrections
- Better outreach to and engagement of the corrections system including in HIV planning
- Training for nursing students and nurses, opportunities for HIV nursing rotations
- Close relationships with schools, including school staff and school health programs
- HIV education in women’s health classes
- Relationships with the PTA and parents to get information and education out to families
- Help distributing the Department of Health and Human Services (HHS)/Walgreens flu vaccination vouchers to needy populations
- Targeted marketing campaigns
- A video presentation on You Tube; use of social media, public service announcements (PSAs), and television programming

Question 2: The strategy impels us to increase coordination and collaboration across HIV prevention, care, and treatment; STD, TB, and viral hepatitis services; mental health and substance use services; housing and other supportive services.

2.1 What potential opportunities for collaboration and coordination of activities do you see?

- Consumer peers
- A follow-up group to this meeting
- An interagency group made up of leaders of small groups
- HCV education and outreach along with HIV education and outreach
- Integrated events that reduce duplication of services
- DCFS networking for children aging out of the system
- Counseling and testing opportunities
Participants mentioned church events, fairs, national and regional testing events, and World AIDS Day.
- Summits of Hope, other correction-related events
- Capacity building and relationships with LGBTQ-serving organizations
- Collaboration and coordination with faith-based working groups, Planned Parenthood and other reproductive health groups, community action agencies, and agencies providing assistance with rent, utilities, etc.
- Education for boards of health
- Networking, training, and education opportunities through the OFS Healthcare nursing system

- HIV education and training for nurses as a requirement for license renewal (the Illinois Department of Financial and Professional Regulations could do this)
- Networking and collaboration with pharmacies—both local and specialty pharmacies
- Collaboration with the education system
Mentioned were regional superintendents, the existing Illinois State Board of Education (ISBE) DASH (Division of Adolescent and School Health at CDC) grant collaboration, and the possibility of replicating that grant in the Region.
- Public access TV production of educational programs

2.2 What are the challenges or barriers to this collaboration and coordination?

- Lack of funding
- Lack of funding for some services
- Lack of funding for small agencies
- Lack of funding for Hepatitis C education, testing, and care
- Unmet needs and limited resources
- Large case loads
- Silos and territoriality
Mentioned were silos based on funding streams, and silos between mental health, substance abuse, public health, and education—each with its own agenda and meetings—and the need to share information, including across websites, so that everyone knows what they need to know about what is going on in other agencies and organizations.
- ACA impact on service availability and access
- Distance between major populations, communities, and services—difficulty knowing exactly where to target services, a drain on resources, and lots of travel time required for clients and providers
- Distance-isolated areas and lack of transportation between communities
- Limited service hours
- Limited testing at some organizations
- Referral system difficulties
- Inadequate passion for the work, even in some HIV centers
- Lack of interest in HIV in some organizations that don't see the connection to their mission; competing demands on time, energy, and resources
- Difficulty getting on the agenda of local government, such as city councils, and churches
- Lack of awareness of HIV and HIV services
- Limitations on services for sex offender populations
- Stigma
Specifically mentioned were fear and stigma around being identified as HIV positive by receiving services from an organization or center associated with HIV.
- Cultural and language barriers, social norms
- Religious beliefs
- Legal issues between hospitals and a pending local lawsuit

Question 3: The strategy says three critical steps we must take to reduce HIV infection are:

- (1) intensify prevention efforts in communities where HIV is most heavily concentrated; (2)

expand targeted efforts to prevent infections using a combination of effective, evidence-based approaches; and (3) educate all Americans about the threat of HIV and how to prevent it.

3.1 How do we balance the demand to intensify targeted interventions for the most impacted populations and the need to provide general education and prevention services?

- Work with local health departments
The thought was that local health departments know the gaps and resources in their areas, they know which groups are open and receptive to learning about HIV, and they know how to get things on the agenda at local meetings.
- Increase reproductive health services in the area
- Establish more venues for routine screening
- Raise awareness of the need to get tested in the absence of symptoms
- Talk more about sexual risk behaviors
- Use targeted interventions and messaging for the zip codes with the highest HIV rates, and use general messaging for the rest of the county; strategize for reaching the most affected populations first
- Use nontraditional outreach models, and use different methods to reach people who don't disclose risk
- Use effective advertising to get HIV prevention education and awareness messages out every day
- Use social media including as an outreach strategy in areas that are not targeted and in areas where people don't want to talk about HIV
- Use colleges and universities to launch initiatives that the local health department is unable to do; use graduate students for student internships and projects
- Make HIV education a robust part of medical school and continuing education requirements for doctors; offer third year medical students a rotation through HIHAC
- Raise health care provider awareness that HIV screening is an essential benefit under the ACA has been given an "A" grade by the U.S. Preventive Services Task Force
- Increase health and HIV education in schools
Mentioned were using regional superintendents to make spreading the word easier, stressing that HIV is not a gay disease, and dispelling the myth that medication makes HIV an easy disease.

3.2 Federal and State HIV prevention funds for Illinois were cut this year and may be cut in future years. Knowing that, what recommendations can you provide the State about ways to best intensify prevention efforts in communities where HIV is most concentrated?

- Award funding in ways that reduce territoriality and fighting for funds
- Remove classifications, labels, and targeting that create barriers
- Use routine opt-out HIV testing for all populations.
- Stop tiptoeing around the topics of sex education and HIV education; bring them out in the open as with any other chronic disease outreach
- Educate all at a younger age to shape social norms; for example, make comprehensive science-based sexuality education required in all schools in the state

- Use young people for prevention efforts targeting youth; tailor language and expressions for youth
- Use scan codes rather than brochures
- Ask the Illinois Department of Financial and Professional Regulation to require HIV training for professionals' license renewal
- Use social media to locate and educate high-risk populations
One idea was to use extra money from fee for services to advertise on social media since low income communities also access social media. Others included using social to reach youth such as advertising high school and university testing days on social media.

3.3 What HIV health inequities do you see and what strategies can you suggest to address them?

- Consider HIV in the same way as other chronic diseases to reduce stigma
- Promote and support local people living with HIV as the face of HIV in their communities
The idea was to make HIV personal and to empower them as leaders in their community who could speak at schools and community events about what it's like to have HIV.
- Address the increasing proportion of HIV among youth and black MSM, especially low-income MSM with low educational levels
- Overlay HIV data in minority communities with other data such as unemployment, STD rates, housing, teen pregnancy, and incarceration to raise awareness and get a complete picture
- Establish an HIV agenda to raise awareness in the African American community about HIV disparities
- Partner with organizations that have the required 51 percent African American board membership and are interested in African American AIDS Response Act (AAARA) funds
- Work with local faith-based partners to promote more HIV education
Ideas included the need to start the conversations with local pastors, especially some of the younger pastors; to find the right ways to educate and train the pastoral community; and to join interfaith organizations.
- Provide mental health and substance abuse treatment, and provide training to increase case managers' knowledge of mental health a substance abuse issues
- Increase the availability of dental health care and services
- Offer job training to help people living with HIV increase their economic stability and their status in life
- Increase health literacy, especially among low-income populations
- Address inequities in prescribing pre-exposure prophylaxis (PrEP) and non-occupational post-exposure prophylaxis (nPEP) and in the ability to access them
- Educate people who are addicted to drugs about PrEP
- Provide clinicians with training on PrEP and nPEP, and offer continuing medical education (CME) for physicians
- Address HIV fatalism, especially among young people
- Work to reduce stigma among HIV-positive minorities, which exacerbates inequities by reducing the number of people who stay in care services and reach undetectable viral loads
- Counter the "no symptoms, no problem" belief

Question 4: Comprehensive prevention services (including partner services) for persons living with HIV are a priority of the strategy.

4.1 What needs to be done to ensure HIV-positive individuals have access to prevention, care, treatment, and supportive services to decrease the risk of HIV transmission to their partners and retain them in care?

- Focus on viral load suppression
- Identify clients who are diagnosed but not in care and those who have been lost to care
- Use retention in care workers
- Link with general services to create one-stop shops in order to reduce stigma
- Take services to mobile units and satellite offices
- Make free condoms more easily available (people know they are free through the health department, but the health departments cannot get them in the numbers they did in the past)
- Target drag shows, and speak to the audience or do HIV education during intermissions
- Improve communication between prevention and case management so that prevention knows that newly diagnosed and referred clients have been enrolled and are in care
- Enhance medication follow up and adherence by communicating referrals consistently with medication providers
- Educate providers more on treatment adherence, peer support, retention in care, and protection of confidentiality
- Build relationships with medical providers to increase the communication between them and their patients about treatment adherence, drug tolerance, and side effects
- Work with local fraternities to help with educational and fundraising opportunities for HIV organizations

4.2 What does your organization need to incorporate prevention for HIV positives into its array of services?

- Capacity building and technical assistance
- More education and training for organizations and staff
Recommended were core training for providers; more presentations with outside speakers to keep the education and training up with current issues and trends; the pairing of medical professionals and peers as co-trainers; and education for all staff in an organization on culture sensitivity, referral, partnerships, and creating relationships.
- Permission to test outside of grant scopes so grantees don't have to turn people away
- More collaboration—for example, Central Illinois FRIENDS of People with AIDS would like a relationship with HIHAC
- Support for sero-discordant couples
- The ability to communicate to clients the need for them to identify their partners
- Education for all clients so that they have a basic knowledge of HIV, and education for clients so that they know where to get tested for free—information that they will pass to their partners and peers

4.3 What are some challenges or barriers your organizations face in providing comprehensive prevention for positives services?

- Limited funding
- Funding restrictions
- Grant guidelines and requirements, and bureaucracy around receiving funding
- The need for capacity building
- Not enough collaborations
- Prevention for positives as a low priority for clients who are dealing with multiple life crises
- Health literacy among clients
- Restrictions on sexuality and HIV education in schools including limited discussions about sex and the inability to offer condoms in schools
- Stigma

Question 5: To identify ways to mitigate the impact of stigma and discrimination on HIV care, treatment, and prevention. In Region Two, the latest epidemiological data suggest the following:

There were 188 new cases of HIV infection diagnosed in Region Two between 2008 and 2012. This figure represents an average of 37 cases each year. There were 25% fewer cases diagnosed in 2012 compared to 2008 (40 cases in 2008, and 30 cases in 2012). Illinois experienced a 6% decrease in the number of new cases in this same period. The proportion of new cases that were male fluctuated between 2008 and 2012. In 2008, 60% (N=24) of all new cases were male. The proportion of new infections diagnosed among males increased to 90% (N=37) in 2010, and, by 2012, 83% (N=24) of all new cases were diagnosed among males. Overall, males represented 80% (N=150) of all new HIV diagnoses between 2008 and 2012.

The proportion of new cases diagnosed among blacks increased from 35% (N=14) in 2008 to 60% (N=18) in 2012. Blacks and whites accounted for nearly equal proportions of all new cases diagnosed between 2008 and 2012 (45% among each group, on average). Hispanics represented 4% (N=8) of all new HIV infections diagnosed between 2008 and 2012.

The proportion of new infections diagnosed among persons in the 20-29 age category increased from 30% (N=12) in 2008 to 37% (N=11) in 2012. In 2011, an unprecedented 45% (N=14) of all new infections occurred among 20-29 year-olds. Overall, 37% (N=69) of people diagnosed between 2008-2012 were in the 20-29 age category at the time of diagnosis, followed by 40-49 year-olds (18%) and 30-39 year-olds (16%).

Men who have sex with men (MSM)—particularly white MSM—represent a significant proportion of HIV new infections. MSM accounted for 63% of new infection between 2008 and 2012 (N=99) and 70% of new infections in 2012 (N=16) (among all cases with a reported risk). White MSM accounted for 52% (N=51) of all infections diagnosed among MSM between 2008 and 2012, followed by blacks (41%, N=41) and all other racial/ethnic categories (7%, N=7). There has been an increase in the proportion of new infections among MSM that are black—blacks represented 33% of all new infections among MSM in 2008 and 69% of all new infections among MSM in 2012. Between 2008 and 2012, heterosexual contact was attributed to 84% (N=27) of all new infections among women for whom a risk was reported.

5.1 What does your organization need to implement effective, appropriate interventions for these populations?

- Money, more funding
- More training and education
Mentioned were the following: cultural sensitivity training that covers topics in addition to race and ethnicity, humility training for physicians, education and training on how to de-stigmatize HIV in high-risk populations, education and training for staff about HIV and available resources, education on how to effectively educate people about HIV.
- Access to meetings by phone
- Sharing of information between prevention and care
- Staff to engage people—staff with knowledge and passion for the work
- More effective ways to work with injection drug users
- Ways to share best practices, a list of best practices from IDPH
- Testing as a routine part of preventive health care (also reduces stigma)
- Health awareness
- Outreach to churches
- Diagnosis of youth in high school
- Networking with Boys and Girls Clubs to mentor and support youth at risk
- More effective use of social media

5.2 What needs to be done at the structural level (policies, laws, and infrastructure) to reduce stigma and to ensure clients have access to services that are culturally appropriate?

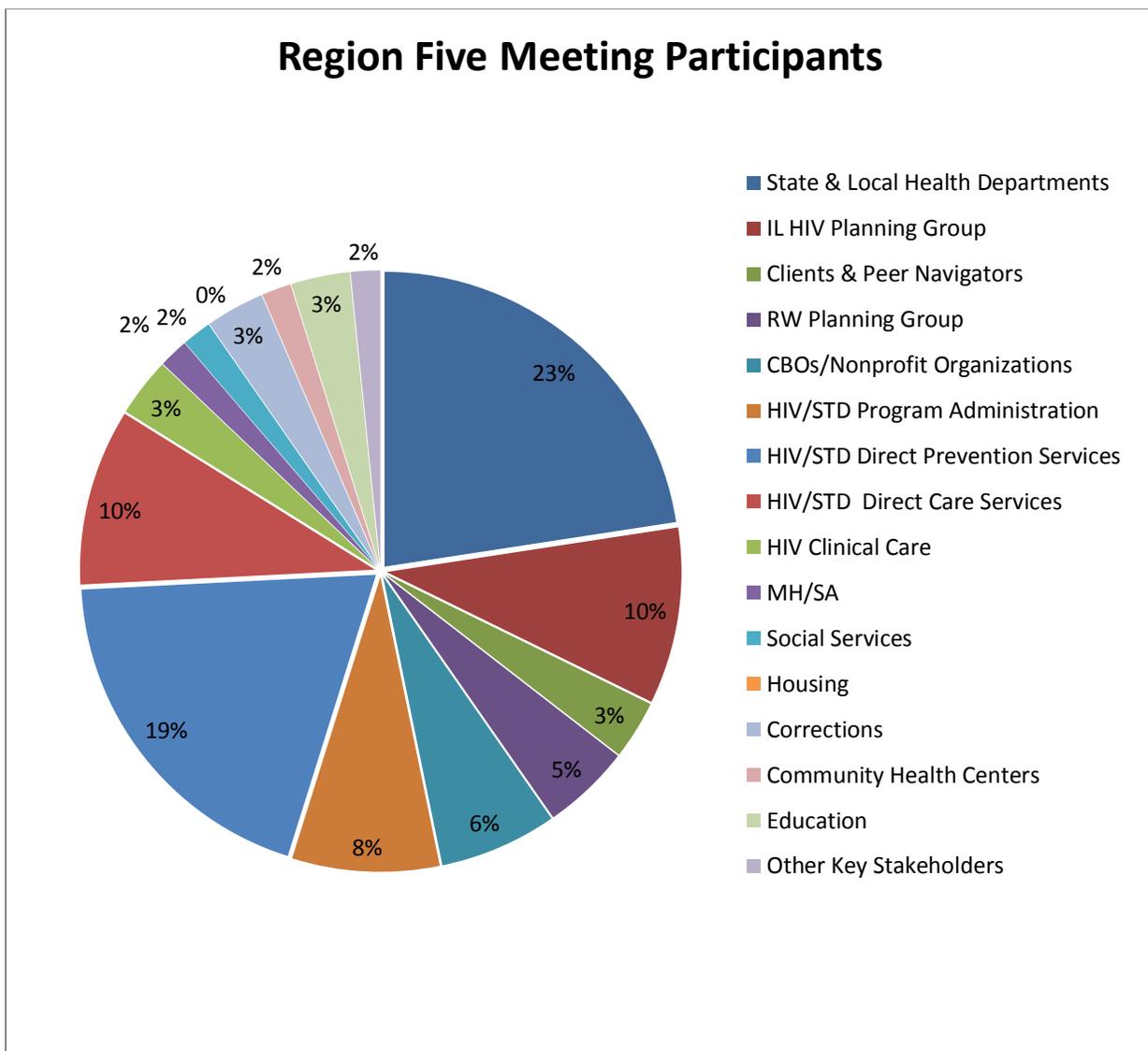
- Have meetings like this one regularly to help people connect and build partnerships
- Increase collaboration and inter-organizational linkages among agencies
- Add multi-language and hearing impaired services
- Make messages bolder to reach targeted populations (the recent meth commercials are an example)
- Package HIV awareness and education in a way that de-stigmatizes it in the community as just another chronic disease—change the culture around HIV; work on the messaging so that HIV is an everyday discussion, as with other diseases
- Help clients address stigma within themselves—the fear of being seen at services, for example
- Keep some of the education and outreach local so that it has a local flavor and language and becomes part of local conversations
- Start education and outreach in communities of color with leaders from within the community rather than outsiders coming into the community
- Make sure that HIV resources are present and accurate in outreach and referral sites such as the United Way 211 website
- Provide paper copies of documents for those who do not have Internet access
- Provide more HIV education and comprehensive sexuality education in the schools—start earlier and make it age appropriate, from elementary to higher education
- Develop a legislative agenda
- Standardize HIV testing into law
- Get HIV on the agenda of city council meetings
- Create a listserv to keep stakeholders abreast of policy issues
- Involve clients in the legislative process and lobbying, help them tell their story

- Rethink all HIV criminalization laws; ensure they are not preventing people from getting tested and in care
- Lift the federal ban on syringe exchange

The Region Five—Southern Illinois Meeting

The Region Five stakeholder engagement meeting was held on August 7, 2014 at the Holiday Inn Hotel and Conference Center in Carbondale. Fifty-five people were invited; 23 attended. Figure 4 shows a breakout of participant affiliations.

Figure 4



About Region Five

Region Five—Southern Illinois includes the following counties: Alexander, Edwards, Franklin, Gallatin, Hamilton, Hardin, Jackson, Jefferson, Johnson, Massac, Perry, Pope, Pulaski, Saline, Union, Wabash, Wayne, White, and Williamson. The Region Five care lead agent is Jackson County Health Department, and the prevention lead agent is the Illinois Public Health Association. For more information, see Region Five: Heart of Illinois HIV Care Connect, <http://www.hivcareconnect.com/heartofillinois.html>.

Although Illinois experienced a 5 percent decrease in the number of new HIV diagnoses from 2009 to 2013, Region Five saw an increase of new diagnoses during that period—47 percent more cases were diagnosed in 2013 compared to 2009. There was an average of 21 new HIV diagnoses in the Region each year since 2009. The rates of HIV incidence and prevalence in several Region Five counties surpass those of the Collar Counties.

Males represented about 80 percent of all new HIV diagnoses in the Region from 2009 to 2013. Women represented just 20 percent of new diagnoses during that period; 71 percent of those diagnoses were attributed to heterosexual contact. There were 29 percent fewer diagnoses among women in 2013 compared to 2009. Blacks made up 47 percent of new cases in 2009; in 2013, they accounted for 39 percent. Overall blacks and whites accounted for nearly equal proportions of all new cases diagnosed between 2009 and 2013 (42 percent and 47 percent respectively). Among MSM, whites accounted for 51 percent of all new HIV infections diagnosed among MSM between 2009 and 2013.

Discussion Questions and Responses

Question 1: The strategy impels us to engage entities from HIV prevention, care, and treatment; STD, TB, and viral hepatitis; mental health and substance use; housing; related supportive services; and other key stakeholders in HIV planning.

1.1 What other entities need to be engaged in this process and at what level (referral, planning) should they be engaged?

- Department of Children and Family Services (DCFS)
- Behavioral health providers, such as Centerstone, and treatment facilities such as Gateway Alcohol and Drug Treatment Center, The Fellowship House, and Women’s Center program for Women in Recovery
- African American churches
- Department of Corrections (DOC), juvenile justice
- Health care advisory boards
- Hospitals and hospital systems, hospitals, medical clinics, Federally Qualified Health Centers (FQHCs), and other health centers
- Medical and nursing system and providers
Participants mentioned OB/GYN providers, pediatricians, parish nurses, medical schools and faculty, and residency programs.

- Universities and colleges
Participants mentioned Southern Illinois University Carbondale (SIU) including several of its programs such as its library newsletter and sports teams.
- Local school districts
- Parents
- Women and girls conferences
- Social media, especially MSM social media (Grindr, Adam4Adam)
- Media such as radio stations, CIL, WDBX, Queer Out Loud

1.2 What would you like to see come out of these planning efforts?

- More cohesive working relationships between state and local agencies
- More collaboration among local agencies
- More routine testing
- More and better HIV education and sexual diversity health training for medical providers
- Much more HIV and sexuality education in the schools
- Social media ads on topics such as effective condom use, targeted testing promotion, linkage to care promotion, especially on MSM apps

Question 2: The strategy impels us to increase coordination and collaboration across HIV prevention, care, and treatment; STD, TB, and viral hepatitis services; mental health and substance use services; housing and other supportive services.

2.1 What potential opportunities for collaboration and coordination of activities do you see?

- Annual IDPH visits to rural communities to discuss HIV and HIV services
- Opportunities to allow multiple agencies to provide input or share information about programs, resources, and costs
- Collaboration on training
- Midwest AIDS Training & Education Center (MATEC) training on HIV and Hepatitis C
- Provider training to make HIV testing more routine, thus reducing stigma
- Routine testing in County correctional settings
- Harm reduction contacts for people leaving treatment facilities
- Harm reduction resource cards statewide—add to the HIV Care Connect website
- Anti-bullying campaigns to reduce LBGTQ abuse
- Coordination between DCFS and health workers to reach children transitioning to adulthood with HIV education
- School board members at the table more often
- Train the trainer programs to develop youth leaders, collaboration with student groups
- Collaboration with media outlets

2.2 What are the challenges or barriers to this collaboration and coordination?

- Limited manpower
- High employee transfer and turnover rates
- Rural issues
Participants mentioned large rural geographic areas, transportation challenges including no mass transit system, and a lack of physicians.
- Difficulty getting certain medical services that require blood draws such as for Hepatitis C with co-infections
- Staffing issues within the local county jails (barrier to testing)
- Competition between churches and community groups
- Lack of acceptance in the community for needle exchange and harm reduction
- SIU control of the content going to students
- Stigma and distrust

Question 3: The strategy says three critical steps we must take to reduce HIV infection are:

(1) intensify prevention efforts in communities where HIV is most heavily concentrated; (2) expand targeted efforts to prevent infections using a combination of effective, evidence-based approaches; and (3) educate all Americans about the threat of HIV and how to prevent it.

3.1 How do we balance the demand to intensify targeted interventions for the most impacted populations and the need to provide general education and prevention services?

- Target programs around the most at risk populations
- Create a shared email list or listserv
- Promote routine testing to providers
- Intensify education in the community
- Get medical facilities in area to adopt fourth generation testing; get Quest Labs to adopt and promote fourth generation testing
- Use AmeriCorps student workers to help with general education and prevention services—trained through train the trainer programs
- Get pharmacies to stock HIV Care Connect brochures with their home tests
- Use CDC’s professionally produced videos and materials—both for targeted channels with risk-targeted messages and general channels with general population messages
- Use public information and social media campaigns such as Greater Than AIDS and CDC’s Act Against AIDS
- Develop and use more PSAs

3.2 Federal and State HIV prevention funds for Illinois were cut this year and may be cut in future years. Knowing that, what recommendations can you provide the State about ways to best intensify prevention efforts in communities where HIV is most concentrated?

- Plan how to better address the most at risk populations in the hardest hit areas
- Base grant scopes more on epidemiological data in the local geographic area (very different from the rest of the state)
- Develop and implement a PREP initiative as part of the Department’s prevention toolkit of resources

- Share responsibilities at the local level through collaborative efforts and information sharing
- Target migrant workers for HIV preventions services
- Connect the new Regional Implementation Group harm reduction project (Sisters & Brothers) to sites serving injection drug users (IDUs) and communities with IDU infections (focus on methamphetamine injection in the Region)
- Partner with universities; encourage SIU to allow student access to clean needles
- Provide more education for parents
- Use social media campaigns
- Engage the local media

3.3 What HIV health inequities do you see and what strategies can you suggest to address them?

- Lack of funding to address all needed testing services
- Inability to use federal funds for certain services
- Lack of services in migrant communities
- Lack of HIV knowledge among local physicians (strategy is to provide them with consultations with specialized physicians)
- Lack of providers and, in some cases, funding for women's health services for women living with HIV
- High rates of new infections among IDUs and among Black MSM
- Stigma (strategy is to change policies and laws)

Question 4: Comprehensive prevention services (including partner services) for persons living with HIV are a priority of the strategy.

4.1 What needs to be done to ensure HIV-positive individuals have access to prevention, care, treatment, and supportive services to decrease the risk of HIV transmission to their partners and retain them in care?

- Make people living with HIV aware of resources, provider choices, the importance of viral load suppression to health, and the lowered—not reduced—risk of transmission to others when viral load is suppressed
- Create incentives for HIV-positive individuals to reengage with care
- Make sure all providers know about and make referrals to Ryan White care services
- Increase the number of mental health care providers in the region
- Identify and share information about best practices among agencies
- Provide transportation; create an inter-county mass transit system
- Engage primary medical providers to support and maintain connections with their newly diagnosed patients, rather than pass them off as referrals
- Provide more support groups
- Hold monthly meetings with providers and multidisciplinary meetings with providers
- Create a paid Positive Youth Peer Navigator positions (students are not out about being positive)

- Use social media to communicate accurate messages about HIV and to inform people about services
- Advocate with the legislature

4.2 What does your organization need to incorporate prevention for HIV positives into its array of services?

- Money
- Money for advertising
- Provider training
- Sharing of model policies and procedures for prevention for positives
- Collaboration with the Jackson County Health Department
- Updated equipment for fourth generation testing
- Telemedicine linkage
- Routine HIV testing; required third trimester HIV testing

4.3 What are some challenges or barriers your organizations face in providing comprehensive prevention for positives services?

- Reporting requirements and administrative burdens
- Lack of resource personnel
- Judgmental providers
- Lack of people's champions—peers or providers
- Too few support groups and difficulty engaging participants because of stigma
- Stigma including stigma around sexual risk, fear of disclosure, and fear of being out as positive

Question 5: To identify ways to mitigate the impact of stigma and discrimination on HIV care, treatment, and prevention. In Region Five, the latest epidemiological data suggest the following:

There was a 47% increase in the number of new cases diagnosed between 2009 and 2013 (19 new cases in 2009 and 28 in 2013). An average of 21 new HIV cases was diagnosed each year during this time period. The majority of new infections diagnosed among males and females from 2009-2013 were white. The proportion of new cases diagnosed among males and females attributed to IDU was significantly greater in Region Five compared to statewide figures (10% vs. 5%). Among males, the majority (42%) of new infections occurred among those in the 20-29 age category. Among females, the majority (35%) of new infections occurred among those in the 30-39 age category; however, a significant proportion (25%) of infections occurred among those in the 19 and under age category. More than one-third (34%) of new cases diagnosed between 2009 and 2013 were between the ages of 20-29 at the time of diagnosis; 14% of cases were 19 years old or younger.

5.1 What does your organization need to implement effective, appropriate interventions for these populations?

- Financial resources
- Support for peer navigation
- Support for women’s groups
- Implementation of IDU harm reduction services
- Education for school boards
- Comprehensive HIV and sexuality education in the schools; possibly with buy-in through the regional offices of education
- Programs with parental engagement
- Skype social groups
- MSM social media outreach in the absence of local gay bars or LGBTQ organizations
- Reduced stigma around women and HIV
- Implementation of IDU harm reduction services

5.2 What needs to be done at the structural level (policies, laws, and infrastructure) to reduce stigma and to ensure clients have access to services that are culturally appropriate?

- Engage local churches
- Eliminate Department of Corrections policies that fail to address the needs of HIV-positive individuals in the corrections environment
- Make HIV testing routine
- Provide more support groups
- Engage Southern Illinois University
- Inform and educate school boards, which are often more conservative than teachers, about HIV
- Increase HIV and comprehensive sexuality education in the schools
- Engage local youth organizations
- Make sure front line worker have a voice when policies and laws are being written

The Region Seven—Collar Counties Meeting

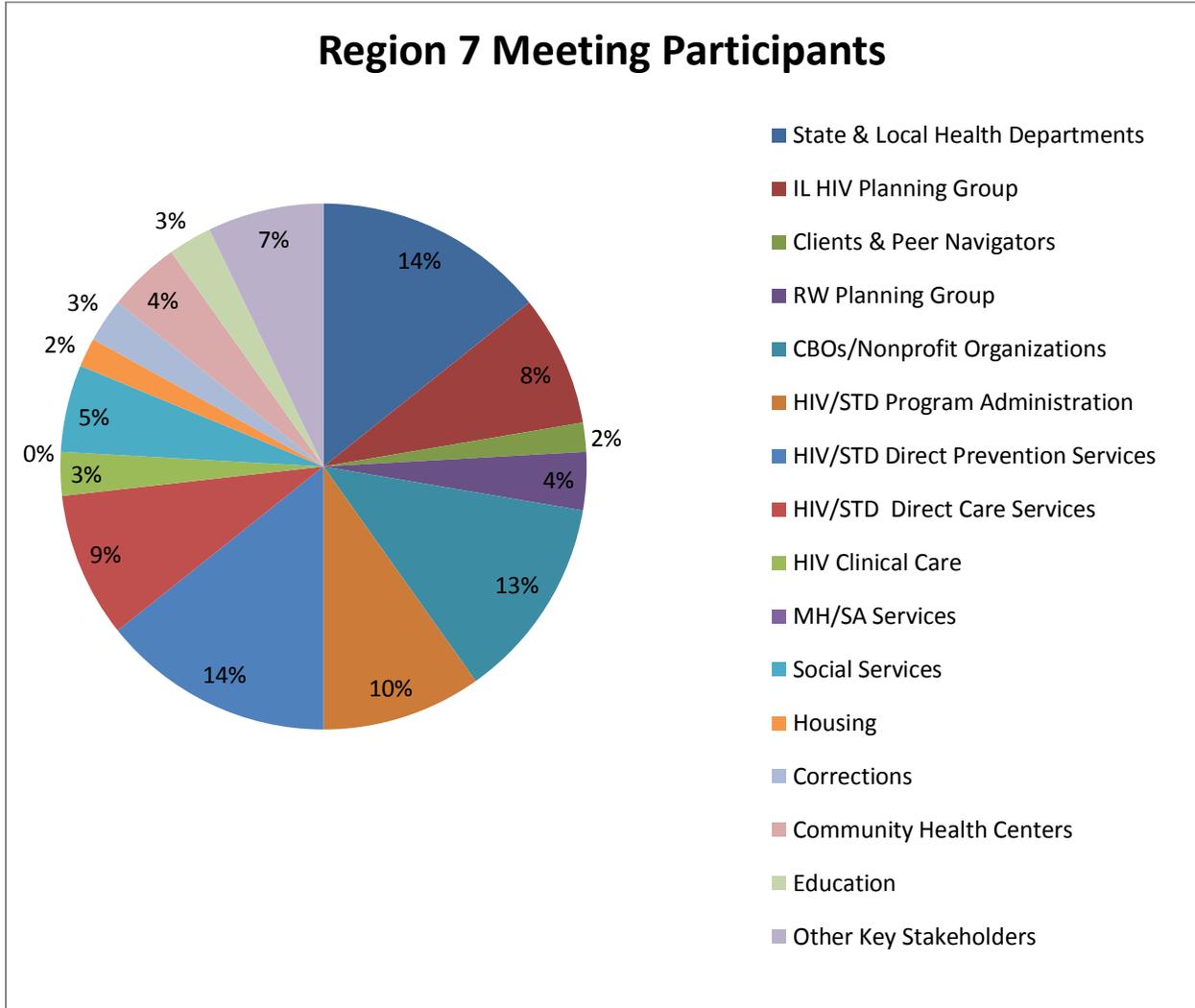
The Region Seven stakeholder engagement meeting was held on April 11, 2014 at Elmhurst College in Elmhurst. Thirty-eight people attended; 114 were invited. Figure 5 on the following page shows a breakout of participant affiliations.

About Region Seven

Region Seven—Collar Counties includes the following counties: DuPage, Grundy, Kane, Kendall, Lake, McHenry, and Will. The care lead agency for Region Seven is AIDS Foundation of Chicago, and the prevention lead agent is the Illinois Public Health Association. For more information, see Region Seven: Collar Counties, HIV Care Connect, <http://www.hivcareconnect.com/chicagoarea.html>.

From 2008 to 2012, the number of new HIV diagnoses in Region Seven increased by 13 percent at the same time that they decreased six percent statewide. Males represented 77 percent of all new HIV diagnoses in Region Seven during that period, and women represented 23 percent.

Figure 5



Eighty-eight percent of new diagnoses among women were attributed to heterosexual contact. There was a 42 percent increase in the number of new cases diagnosed among women in 2012 compared to 2011.

Between 2008 and 2012, blacks accounted for 33 percent of all new cases in Region Seven, followed by whites at 32 percent, and Hispanics at 28 percent. The number of new cases diagnosed among whites decreased 9 percent between 2008 and 2012, while the number of cases diagnosed among Hispanics and blacks increased by 41 percent and six percent respectively. The proportion of new cases diagnosed among Hispanics increased from 25 percent in 2008 to 33 percent in 2012. MSM, particularly white MSM represented a significant proportion of new HIV infections between 2008 and 2012. Overall, MSM accounted for 64 percent of new infections during that period: 37 percent of all MSM infections were among whites, 30 percent were among Hispanics, and 29 percent were among blacks.

Discussion Questions and Responses

Question 1: The strategy impels us to engage entities from HIV prevention, care, and treatment; STD, TB, and viral hepatitis; mental health and substance use; housing; related supportive services; and other key stakeholders in HIV planning.

1.1 What other entities need to be engaged in this process and at what level (referral, planning) should they be engaged?

- Consumers
Specifically mentioned were youth and youth who are aging out.
- Funders
- Township and city managers and leaders
- Northern Illinois Public Health Consortium (NIPHC)
- Kane and Kendall Counties; all local health departments
- Department of Corrections, local corrections systems
- Department of Aging
- Mental health planning community resource team
- Community leaders—the people who others in the community listen to
- Churches, faith-based communities and organizations
- Senior serving organizations
- Agencies and organizations serving women including Planned Parenthood
- Agencies and organizations serving people of color including minority health organizations and providers
- Immigrant and refugee serving organizations
- Youth serving agencies and organizations
- Agencies serving LGBTQ populations
- Substance use and behavioral health organizations; organizations serving drug using populations
- Housing agencies, homeless shelters
- Juvenile justice organizations
- Domestic violence organizations
- Plasma centers
- Hospitals, clinics, and health care providers
Participants mentioned hospitals and clinics serving uninsured and underinsured populations, private hospitals and health care providers including behavioral health care providers, primary and secondary care doctors, infectious disease specialists, and dental care providers.
- Adult literacy organizations and providers
- Organizations serving youth in and aging out of child welfare
- The education system at all levels
Participants mentioned the Illinois State Board of Education, school boards, elementary schools, high schools, school nurses, and teachers.
- Local legislators

1.2 What would you like to see come out of these planning efforts?

- More people who know their status
- The patient put first in both care and prevention services
- Movement toward meeting ILHAS goals
- Action upon the ideas generated
- Regular reports on outcomes from these planning efforts
- Stronger consumer support and involvement including stronger consumer advisory boards to identify needs and gaps
- More people at the table, a more diverse group of people at the table
- An organization that sets the agenda for HIV across the state, by people infected and affected by HIV
- A stronger voice in the Collar Counties when it comes to dividing the resource pie
See Appendix G for more information about building suburban care capacity.
- A possibility of a share of the resources for smaller and newer organizations
- Fewer reporting systems
- Education and accountability
- HIV standards of care addressed
- Information about the barriers to testing for providers—why they are not testing
- More collaboration and fewer silos
- More connection between care and prevention
- More agencies that know what other agencies are doing
- Collaboration among organizations, better communication, shared data
- Enhanced, established communication
- Help for individuals on how to navigate the health system
- A contact and referral list
- IDPH/MATEC maps showing Ryan White providers and what they offer
- Help making connections and linkages
- More mobile testing by local agencies
- More outreach to providers, especially private providers on standards of HIV care
- Provider education on the importance of screening
- Help for providers on conversations about sex with patients
- Education and information for new providers on cultural competence, HIV stigma, and other topics to prepare them to see HIV-positive patients now insured through the ACA
- Exemplary health education in the schools
- Independent advisory groups (such as consumers)
- More social media networking and replication
- Local community anti-stigma coalitions
- Stronger advocacy in the regions

Question 2: The strategy impels us to increase coordination and collaboration across HIV prevention, care, and treatment; STD, TB, and viral hepatitis services; mental health and substance use services; housing and other supportive services.

2.1 What potential opportunities for collaboration and coordination of activities do you see?

- More coordination between the IDPH HIV and STI sections
- IDPH guidance to local agencies to collaborate more—STI/HIV/Ryan White
- IDPH guidance on integration, program collaboration, systems integration (PCSI)
- HIV-positive individuals willing to put a face to the disease
- Coordination among ACA marketplace plans, Medicaid, and Medicare
- An association in each underserved county offering conferences and other resources with information specific to the needs and interests in the county
- Outreach to volunteer and community organizations to develop champions
- Empowering clients and training peer navigators
- Representation by mental health, substance abuse services, housing, and supportive services at meetings to improve communication, networking, and referrals
- Better collaboration with Chicago Department of Public Health (CDPH) and Cook County Department of Public Health (CCDPH) on data matching—STD, HIV, prenatal HIV with congenital syphilis
- More integrated programs at the local level
- Collaboration among providers to maximize the impact of funding
- Opportunities to learn from each other about best practices, about what works and what does not
- Better coordination and collaboration between organizations funded to do surveillance and care
- Better coordination and collaboration with mental health and substance use providers
- Better coordination and collaboration with corrections and county jails
- Better coordination and collaboration with faith communities
- Partnerships with state and local legislators around access to faith communities
- Better coordination and collaboration with community centers and senior centers
- Better coordination and collaboration with colleges and universities
- Disease Intervention Services (DIS) designees
- More engaged hospitals and health care providers
- Medical school curriculum on the importance of serving all patients

2.2 What are the challenges or barriers to this collaboration and coordination?

- Not enough funding
- Competition for funding that inhibits collaboration
- No funding for innovation
- Fighting over grant scopes
- Too much bureaucracy
- Different reporting systems
- Not enough staff, staff stretched too thin
- Ego
- Low prevalence counties

- Lack of interest in rural communities
- Not enough communication
- Too much competition, too little collaboration
- Fee for service competition
- People don't know their status
- People don't get tested because they don't know they are at risk
- Smaller organizations at a funding and capacity building disadvantage
- Inadequate investment in HIV care by CDPH in the suburbs with Ryan White dollars—the investment is not proportionate to the need
- Too few HIV champions among politicians and local community leaders
- Lack of knowledge about the best ways to reach and interact with agencies outside the normal HIV network
- Knowing what information other service agencies need and, sometimes, the information we need
- Language barriers
- Not enough knowledge about working with young MSM of color
- Law enforcement not sensitized to the needs of clients who are addicted, especially IDUs
- Fear and stigma, especially affecting IDUs

Question 3: The strategy says three critical steps we must take to reduce HIV infection are:

(1) intensify prevention efforts in communities where HIV is most heavily concentrated; (2) expand targeted efforts to prevent infections using a combination of effective, evidence-based approaches; and (3) educate all Americans about the threat of HIV and how to prevent it.

3.1 How do we balance the demand to intensify targeted interventions for the most impacted populations and the need to provide general education and prevention services?

- Diversify funding streams, use multiple funding streams
- Promote more collaboration among agencies, even those with the same funding
- Emphasize prevention equally with care; don't take dollars away from care, but make prevention dollars equal care dollars
- Raise awareness that care providers also provide HIV prevention by lowering the viral loads, conducting partner services, etc.
- Fund agencies to provide education
- Get information to county boards of health about meetings like this
- Establish contacts and two-way referrals with more agencies to increase reach and communication
- Get information out to private and public providers to let them know about services
- Reach people with HIV education as part of routine testing
- Provide general education at higher levels—do grand rounds at hospitals, educate our own leadership
- Remind providers about the components of good HIV health care by sending out memos to health networks
- Maintain good relations with hospitals to do more routine testing; reach out to let them know how to link clients to the care system

- Raise awareness about the need for immediate treatment, rather than waiting for CD4 levels at 200 or lower—treatment is prevention
- Look at larger networks as partners to leverage resources to reach vulnerable populations
- Identify one group in the community and start there
- Reach out to Balm of Gilead for information on reaching young black MSM who engage in risky behaviors
- Explore under-utilized interventions for positives
- Collaborate with agencies that serve targeted groups such as Boys and Girls Clubs and YMCA/YWCA to reach youth
- Reach out to political partners for help getting on the agenda and in front of school boards to tell the basic story of the HIV continuum of care (aka the Gardner Cascade)
- Educate providers that abstinence is ineffective and is not the only message
- Select research-vetted, behaviorally effective curricula and engage the school systems
- Build a social network of people who come in for testing
- Ensure access to accurate information
- Promote the message that people who are HIV positive are still active, living persons who have loving relations and children
- Normalize the marketing around HIV; the current ads are too targeted
- Use targeted social marketing with messaging targeted to different groups including seniors aging with HIV

3.2 Federal and State HIV prevention funds for Illinois were cut this year and may be cut in future years. Knowing that, what recommendations can you provide the State about ways to best intensify prevention efforts in communities where HIV is most concentrated?

- Upgrade reporting systems
- Address in the grant scopes that no one wants to identify within a risk group
- Remember that level funding is not really level
- Maintain African American Response to AIDS Act funds
- Move funds from lesser impacted areas to more concentrated areas while accessing larger groups with a broader circle of influence
- Help organizations find pro bono support
- Provide ongoing ACA education
- Provide better training on DIS outreach
- Resolve issues around reimbursement for DIS efforts
- Conduct appropriate outcome evaluation of DEBIs
- Sustain what works, cultivate those with passion
- Expand what is considered prevention, such as maintaining basic life needs (hierarchy of needs)
- Provide more data on viral load mapping to help locals target communities and provide prevention outreach
- Use data to drive the work with prevention and testing outreach and to find individuals who are positive and not in treatment
- Use the surveillance data to see how we can better work with and educate providers

- Target physicians who test and find positives to see if they are following up to find out if treatment is occurring
- Explore partnership options for agencies that want to test, such as county jails
- Address behavioral health issues, and get to why the younger generation is not tuning in to the prevention messaging
- Use health fairs for communities at risk; provide or help organizations find funding to set them up
- Promote provision of partner services in a way that doesn't contribute to stigma
- Help get HIV laws changed that add to the stigma of the disease and the DIS process

3.3 What HIV health inequities do you see and what strategies can you suggest to address them?

Inequities

- Poverty
- Overlapping community issues—poverty, unemployment, lack of education
- Population inequities around young black and Latino MSM, women
- Stigma and discrimination that make MSM not want to out themselves
- Bad information, misinformation, and lack of information on the ACA and other insurance venues and what is available to individuals
- Not enough staff education
- Inadequate education for youth—no harm reduction, only condoms and abstinence

Strategies

- Change effected at all levels and across all agencies—education, incarceration, immigration, housing, employment, health
- Incentivize health care
- Census, income, and STI maps to help with targeting prevention and care
- Education, awareness
- More education and outreach to reduce disparities and stigma
- More ACA promotion; education that HIV is a covered disease
- More bilingual programs and staff
- Resource sharing
- Local level engagement
- Working through faith communities
- Syringe availability
- Comprehensive sexuality and HIV education in the schools
- Positive messaging
- Ideas from other successful health campaigns
- Social networking, social media, apps
- HIV normalization and stigma reduction

Question 4: Comprehensive prevention services (including partner services) for persons living with HIV are a priority of the strategy.

4.1 What needs to be done to ensure HIV-positive individuals have access to prevention, care, treatment, and supportive services to decrease the risk of HIV transmission to their partners and retain them in care?

- Remove stringent rules that make it hard for people to access services
- Improve access to electronic medical records—reevaluate policy and policy conflicts among programs
- Make sure that Ryan White dollars are proportionate to prevalence share in Chicago, suburban Cook County, and the Collar Counties
- Promote the ACA
- Promote health insurance literacy (to get and keep people in care)
Mentioned were partnering with in person counselors to assist with linkages to insurance and to care, being well versed with insurance and billing information, teaching providers and clients how to navigate insurance, and teaching clients appointment etiquette—new ways of being responsible as part of the health care paradigm shift.
- Prepare for people who are dropping out of ACA insurance because they can't afford the premiums or deductibles (Lake County is seeing this)
- Promote seamless transitions from testing to care and seamless coordination across the board
- Find ways to promote re-engagement in care
- Address stable housing
- Improve transportation
- Make mental health services available
- Provide essential wrap around services
- Promote wrap around agency successes
- Use back to basics messaging about prevention and treatment
- Educate primary medical providers
- Make sure all providers know that treatment is key and that they need to combine treatment with condoms
- Educate all STI and HIV clinicians about how to have conversations with clients about HIV
- Find and support HIV champions in the medical systems
- Facilitate education on what it means to have a responsible and accountable patient-provider relationship
- Reduce stigma
Ideas included a marketing campaign, an anti-stigma push with “Gilead type” commercials, and getting personal messaging out—the new personal stories with new faces—“I am the face of HIV.”
- Promote community outcry and advocacy

4.2 What does your organization need to incorporate prevention for HIV positives into its array of services?

- Removal of health department barriers in some counties (health department politics)
- More and better collaboration between prevention and care (Ryan White) organizations and providers
- More use of peers and peer programming

- Education for operations level staff
- Training (competencies) on how to reach out to new positives and link them to services at the time of diagnosis
- An elevated role for prevention
- Support from agency administration
- Increased referral options among providers
- Increased access to training for local community partners and agencies
- Cultural humility—knowing how to put the word out about HIV in communities
- Connections to key stakeholders to bring in people at risk
- Medical homes
- A change in the culture among private providers about caring for challenging clients
- Relationships with HIV care providers to supplement their services
- More health department extension into schools (school-based clinics, for example)
- HIV education accessible in the schools, at home, in the community

4.3 What are some challenges or barriers your organizations face in providing comprehensive prevention for positives services?

- Too little and uncertain funding
- Too little time, too few resources
- Staffing issues
- Competing priorities
- Too few incentives
- The inability to bill for services—Medicaid, HMO/PPO, Medicare
- Rivalry among agencies
- Not having the caseload
- Getting clients to buy in and come to services
- No system similar to the Pediatric AIDS Chicago Prevention Initiative (PACPI) for adults
- Uncertainty about where to refer including identifying appropriate referrals for overlapping risks
- No linkages to private providers
- Difficulty making connections with case managers and agencies
- Need for staff training in partner services
- Restrictive laws that limit how outreach and tracking can be done

Question 5: To identify ways to mitigate the impact of stigma and discrimination on HIV care, treatment, and prevention. In Region Seven, the latest epidemiological data suggest the following:

The proportion of new cases that are female declined steadily between 2008 and 2011. In 2008, 24.8% (N=39) of all new cases were female, and, in 2011, 19.9% (N=31) of all new cases were diagnosed among females. The proportion of new cases diagnosed among females increased between 2011 and 2012; 24.7% (N=44) of all new cases diagnosed in 2012 were female. Between 2011 and 2012, there was a 42% increase in the number of new cases diagnosed among

females: there were 31 new cases among females in 2011 and 44 in 2012. Overall, females accounted for 22.9% (N=199) of all new diagnoses between 2008 and 2012.

The number of new cases diagnosed among whites decreased 9.4% (N=5) between 2008 and 2012, while the number of cases diagnosed among Hispanics and blacks increased by 40.5% (N=15) and 6.3% (N=3), respectively. The proportion of new cases diagnosed among Hispanics increased from 24.7% in 2008 to 32.7% in 2012. Overall, between 2008 and 2012, blacks accounted for 33.1% (N=270) of all new cases, followed by whites (32.4%, N=264), and Hispanics (28.3%, N=231).

The proportion of new cases diagnosed among persons in the 20-29 age category increased from 27.4% (N=43) in 2008 to 31.4% (N=56) in 2012. Overall, 32% (N=278) of people diagnosed between 2008 and 2012 were in the 20-29 age category. The number of new infections diagnosed among persons in the 20-29 age category increased 30% between 2008 and 2012 (from 43 cases in 2008 to 56 cases in 2012).

Men who have sex with men (MSM)—particularly white MSM—represent a significant proportion of HIV new infections. MSM accounted for 64.4% of new infections between 2008 and 2012 (N=371) and 61.5% of new infections in 2012 (N=64) (among all cases with a reported risk). White MSM accounted for 36.7% (N=136) of all infections among MSM between 2008 and 2012, followed by Hispanics (29.6%, N=110) and blacks (28.6%, N=106). Between 2008 and 2012, heterosexual contact accounted for 87.8% (N=86) of all new infections among women for whom a risk was reported.

5.1 What does your organization need to implement effective, appropriate interventions for these populations?

- More money
- Continued funding—not everyone is covered by the ACA
- More funding opportunities, especially for youth education
- Funding streams for education
- Use of peers
- Public education
- Consistent and constant messaging
- A plan for increased and more specific outreach based on commonalities in the data
- Collaboration with the faith-based representatives and politicians to open doors for community education
- More education at younger ages, outreach to youth and the education system
- More and better use of and support for social media
Mentioned were prevention education on social media, especially for youth; support for tapping into social media, including ongoing support for developing social media outreach (some agencies have very strict limitations on using social media); and financial and technical support for social media outreach.
- Help from IDPH with educating local health departments and funded agencies to see the evidence base, outcomes, and impact of the social media work
- Personal stories from all (children, women, men)

- Coalitions against stigma, bringing in lawmakers, faith-based and grass roots organizations
- Education for medical providers caring for suburban MSM, who report stigmatizing responses from their medical providers that make them reluctant to access health care services
- HIV discrimination and stigma reduction including more talking about HIV, mitigating the impact of stigma, and finding HIV champions to de-stigmatize HIV

5.2 What needs to be done at the structural level (policies, laws, and infrastructure) to reduce stigma and to ensure clients have access to services that are culturally appropriate?

- Get those with the authority to make decisions to the table
- Balance the need for focused testing with the fact that people are being turned away
- Stop minimizing the public health role in HIV prevention—this chips away at public health
- Address system-wide opposition
- Form more coalitions
- Support peer programs
- Increase public education
- Find ways to reach isolated communities with services (and information for providers)
- Continue working on education and communication with Illinois Department of Corrections (IDOC) on HIV prevention
- Increase IDPH provider education to inform doctors and other medical providers about treatment and prevention guidelines, PrEP, and what is new in the field
- Put teeth behind the issue of people who have been in health systems and haven't been offered testing until they are "late testers"
- Normalize and de-stigmatize HIV testing by agencies and primary care providers
- Make routine testing a standard through medical training and hospital accreditation to reduce stigma around testing
- Increase IDPH's role in advocating with medical schools for better preparation of physicians in the areas of cultural competence, communicating HIV diagnosis, etc.
- Improve policies to get more culturally and linguistically competent doctors and other health care providers
- Reduce physician and other health care provider discrimination against IDUs and MSM through medical school and CME training
- Include LGBTQ risk reduction issues in school sexuality curricula
- Promote SSE (Safe Supportive Environment) as a best practice for schools
- Increase and improve the use of social media and websites
- Offer sensitivity training for law enforcement; decriminalize non-violent drug offenses
- Increase involvement by state legislators and ensure that they have accurate information
- Encourage clients to advocate for themselves at lobby days
- Help real people share their stories with legislators
- Look to community-based organizations to reach out to the legislature to support legislation that is positive for the HIV movement
- Revise the HIV Confidentiality Act to make better communication possible with clients upfront

Common Threads

Common threads connected the outcomes of the three 2014 meetings—Regions Two, Five, and Seven—to each other and to the five other regional meetings held in 2012 and 2013. Some of these commonalities across all eight meetings resulted from the meeting structure and facilitation. Mostly, though, they reflected a shared challenge—the increasing complexity of planning, delivering, and evaluating HIV care, prevention, and treatment services as needs continue to grow and budgets continue to contract.

The following 10 themes emerged from an analysis of the discussions across the regions:

- Funding and What It Can Buy
- Best Practices in HIV Prevention and Care
- Transportation
- Training and Education
- Staffing
- Cultural Competence
- Collaboration and Integration
- Media and Public Awareness
- Stigma and Discrimination
- System Barriers and Opportunities

As in previous years, some discussion responses overlapped themes and were included in multiple categories throughout the analysis.

Funding and What It Can Buy

As expected, all three regions identified funding as a major barrier—both inadequate funding in general and too little money available for certain services such as testing and education. The competition for funding also was seen as contributing to silos and inhibiting collaboration in all regions. In Region Two, funding restrictions and the bureaucracy around funding were considered problematic, and smaller organizations were mentioned as especially at a funding disadvantage in both Region Two and Region Seven, including difficulty competing for scarce funds and managing cash flow to allow for slow or late payments. Much discussed in Region Seven was the perception that the Collar Counties do not receive Ryan White Part A funds in proportion to their share of the EMA’s epidemic. That concern is outlined in more detail in the Region Seven notes in Appendix G.

Transportation

Transportation was identified as a barrier in all three regions. Some Region Two communities were described as distance isolated and remote, and, like Region Five, there is no mass transit system to help clients get to needed services. Although the Collar Counties do have some mass transit, it was not viewed as adequate to serve clients who may need to go into Chicago for services or access services in scattered sites or remote suburban areas.

Best Practices in HIV Prevention and Care

The desire for best practices was apparent across all three regions especially with respect to retention in care, effective use of social media, and serving communities and populations who are disproportionately most affected by HIV such as black MSM and youth. Participants were eager for opportunities to learn from each other and share what works, and a Region Two suggestion was that the Department could create a list of best practices that localities can use or shop from.

Training and Education

Participants across the board recognized the value of training—for themselves and for others. Mentioned most often as desired training topics were: HIV testing, social media strategies, cultural competence, capacity building, peer training, client self-advocacy training, and strategies for reaching and working with high risk populations. In all three regions, there was considerable energy around training and education for physicians and nurses. Among the topics most often suggested were PrEP, communicating with patients on difficult topics, cultural humility and cultural competence, and best practices and standards for HIV care.

Staffing

Staffing as a concern in all three regions focused primarily on too few staff for the workload, although the need for staff to be more culturally competent also was a recurring theme. The latter was seen as a need that could be met with more staff training.

Cultural Competence

Each region identified cultural competence as an important concern. Participants acknowledged difficulty working within and across cultures and saw this as a training need across the board. There was a desire to approach communities with an attitude of cultural humility and to partner with community leaders and champions. Of special concern was a perceived lack of cultural competence among some physicians, and many suggestions were made for related training topics for that group of providers.

Collaboration and Integration

Each region acknowledged many difficulties and concerns around collaboration, but they all saw collaboration and integration of services as key strategies for increasing access to services, improving service quality, breaking down silos and reducing duplication of services, and generally making scarce resources go further. The entities most frequently suggested as needing more collaboration were health and medical professionals and institutions—especially private providers—churches and faith-based organizations, and the public school system at all levels. The ACA system was seen as a necessary new partner including insurers, marketplace plans, and other payers, navigators, and providers. Housing and drug treatment programs also were viewed as essential partners for collaboration, as were organizations serving LGBTQ communities and communities of color. In each region, participants named specific organizations and entities with

which they would like to partner, and, across the regions, they saw the Department as having an essential role in encouraging collaboration through leadership, funding, incentives, technical assistance, and capacity building.

Media and Public Awareness

Engaging the media and using the media to engage the general public were shared strategies in Regions Two and Five. Reaching out to the traditional media, including radio stations, was suggested as a strategy for raising public awareness about HIV prevention and reducing stigma around HIV. Social media was a hot topic across the regions. Participants considered social media a tool for reaching MSM and youth, especially, with HIV prevention and testing messages. Highly targeted social media apps were also seen as a way to reach positive MSM with information about services and retention in care promotions. Region Seven participants were particularly interested in technical assistance and capacity building—including funding—around the effective use of social media outreach and social media sites. And, they saw an important role for the Department in helping organizations demonstrate to local health departments the evidence base, outcomes, and impact for this new category of public health strategies.

Stigma and Discrimination

Across the regions, stigma and discrimination against people living with HIV, LGBTQ individuals, and injection drug users were seen as profound and resistant barriers that keep people at risk away from testing and services. In some areas, HIV stigma was considered more common than discrimination against LGBTQ individuals; in other areas, the reverse was thought to be true. Social media was seen both as a tool to combat stigma by normalizing HIV and as a vehicle for reaching stigmatized populations. Education, advocacy—including self-advocacy—and policy/legislation were the strategies most often suggested for overcoming stigma and discrimination. Churches and faith-based leaders—especially ministers and pastors—were viewed as much-needed partners in reducing stigma, and Regions Five and Seven wanted more HIV champions who could reduce stigma by speaking out (as well as acting in other roles to educate their communities). Certain restrictive laws were held both to promote stigma and to limit the effectiveness of some outreach and tracking.

System Barriers and Opportunities

System barriers and opportunities crossed all other categories in every region. Many of the barriers articulated are rooted in complex, persistent social injustices. Working together, however, stakeholders in Illinois can chip away at even the most intractable to mitigate the resulting health disparities. Fortunately, many lesser barriers can be overcome by intentional changes in system policies and procedures. Scopes in Department-issued HIV grants were mentioned across the regions as a barrier to meeting community needs. They were described as restrictive and overly narrow, denying agencies the flexibility to respond to true local need. Structures for allocating State and federal funding were identified as barriers to collaboration, in that competition for grants and other funding encouraged destructive competition and

territoriality. Smaller and newer organizations were seen as especially at a disadvantage under the current system.

These common threads—and other participant responses—are the foundation for the 2014 recommendations for stakeholders that close this report. Figures 6 through 9 on the following pages show the focus on the 10 themes in each region and across the three regions.

Note that these charts, which depict the responses categorized by theme, are an approximation of the breakout group discussion outcomes. They reflect only the number of times that these themes appeared in the discussion notes and do not capture the intensity of the opinions expressed, the energy certain points generated, or whether a discussion item was one person's opinion or the consensus of the group. Remember, too, that the questions themselves, by design, directed the groups' attention to certain topics, in particular, to collaboration. The full story is in the meeting summaries and, especially, in the notes, which are provided as Appendix F.

Note also the “other” category in this chart set. “Other” is any response that does not clearly fit within the 10 most common themes that emerged from the groups. That analysis is solely for the purpose of the meeting reports. It allows us to summarize hundreds of responses here in an accessible format. There is no more importance or validity attached to a response that falls within the 10 themes than one that was categorized as “other.” The Department and the ILHPG have been using, and will continue to use, the full data set to inform their work.

Figure 6

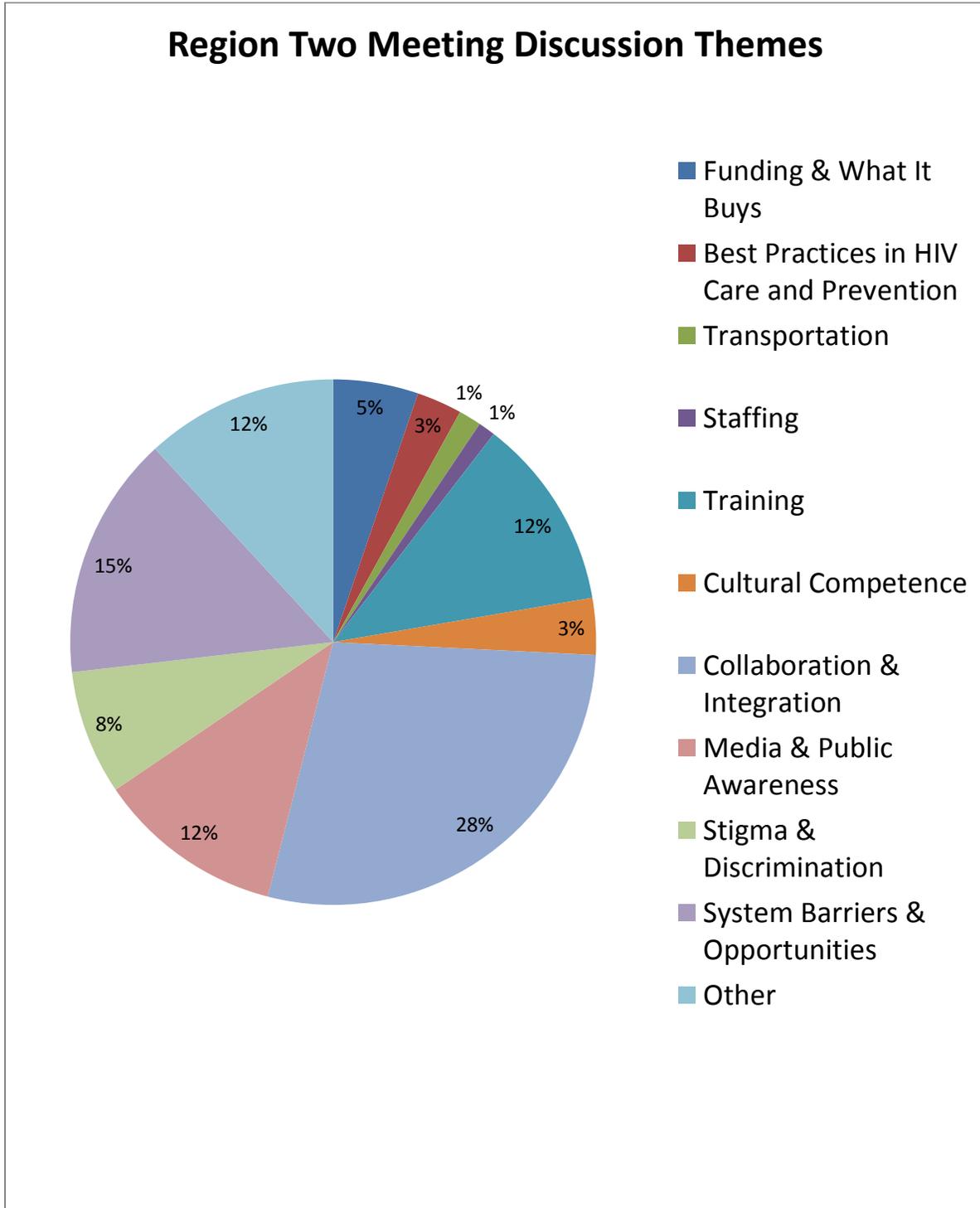


Figure 7

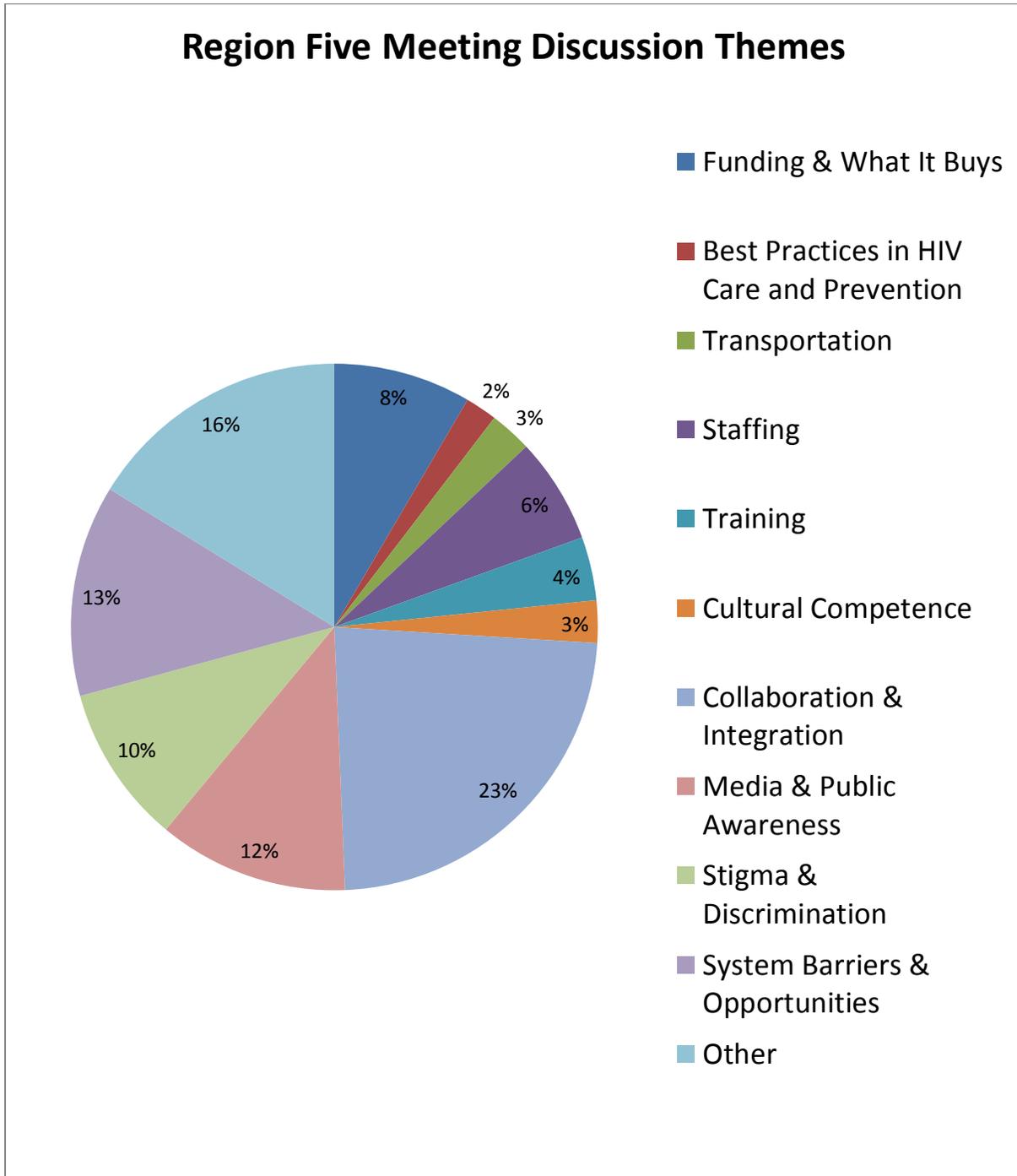


Figure 8

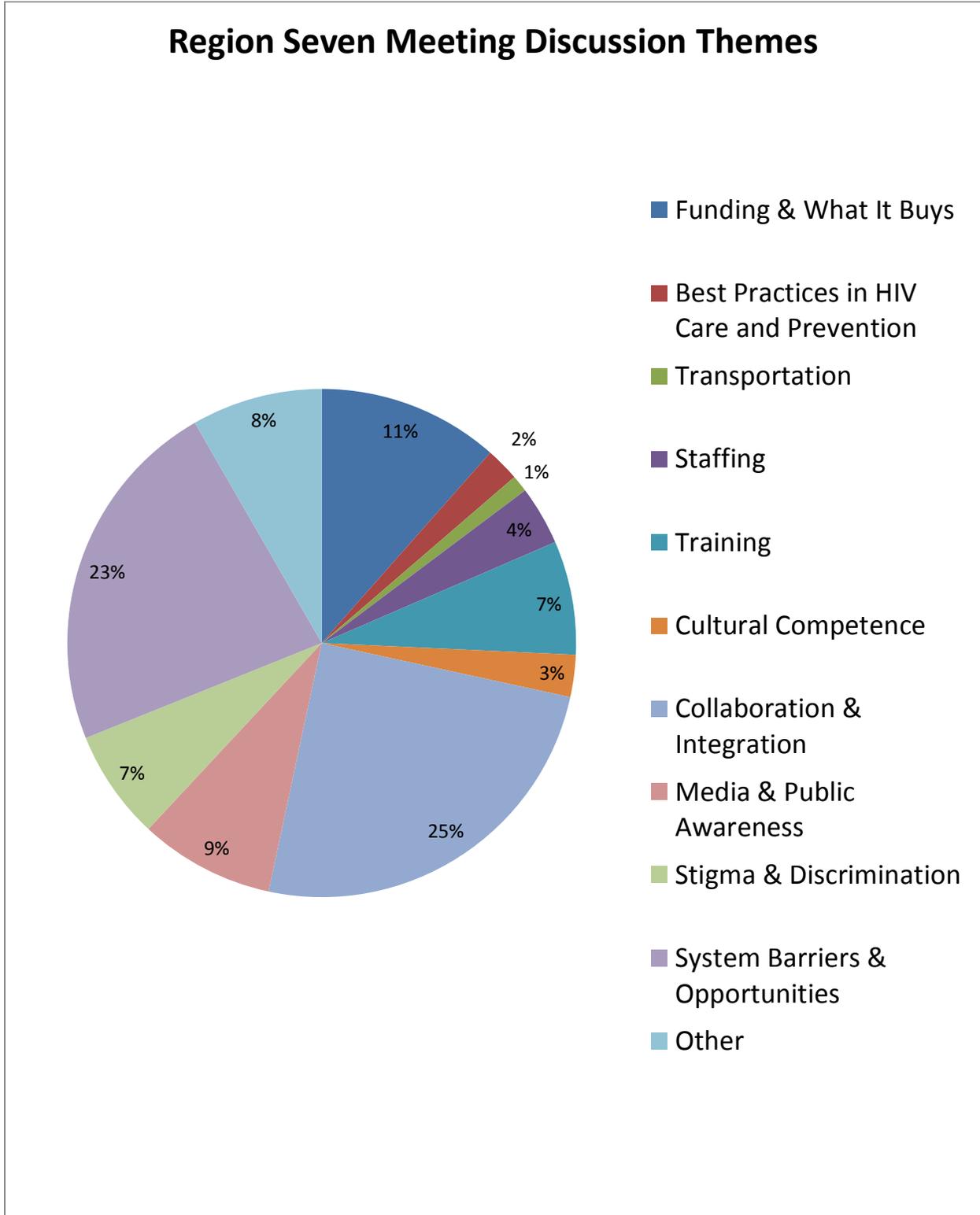


Figure 9



Recommendations for Stakeholders

From the first HIV/AIDS strategy stakeholder engagement meeting in July of 2012 to the last meeting in August of 2014, the Department and the ILHPG learned so much from the people who took part. Those planners, providers, client representatives, and other stakeholders identified not only the service gaps and pressing needs throughout the eight regions, but also the strengths and resources of communities across Illinois that are working together in new ways to solve common problems. The Department and the ILHPG began using the insights and recommendations from the engagement meetings as soon as the first meeting was completed, and each meeting added to the richness of this resource. We are grateful to everyone who participated—and to all who helped plan, conduct, and evaluate the meetings—and we promise you that we will continue to use what you have shared with us to improve the systems of HIV care and prevention services across Illinois.

To close this report and the series of eight regional meetings, the ideas presented below are drawn from the 2014 stakeholder engagement meetings in Regions Two, Five, and Seven as well as the 2012 and 2013 meetings in the other regions. These recommendations can be used to inform the work of federal, State, and local stakeholders across the system as they work to improve the quality and availability of HIV prevention, care, and treatment services in Illinois.

Funding and What It Can Buy

- Make the most of existing funds by enhancing cooperation and collaboration and reducing duplication of services. (2014, 2013, 2012)
- Continue to look for opportunities to optimally plan, implement, and sustain effective HIV care and prevention strategies and interventions. (2014, 2013)
- Commit to stronger collaboration across state agencies to maximize funding that can be directed to services for people living with HIV/AIDS. (2012)
- Help organizations diversify funding streams and tap into pro bono support. (2014)
- Collect and share information about private and public funding opportunities for Illinois HIV prevention and care programs other than State HIV/AIDS resources such as foundation, corporations, and federal government sources that fund health, social services, immigrant and refugee issues, advocacy, antidiscrimination and other areas germane to HIV/AIDS. (2013, 2012)
- Look for funding opportunities related to ACA implantation and Medicaid expansion. (2013)
- Look for creative new partnerships and opportunities to share costs and jointly use resources such as training, space, and administration. (2013)
- Explore co-location and other partnerships that reduce costs. (2012)

Transportation

- Explore strategies that reduce the need for clients and staff to travel long distances such as mobile clinics, subcontracts with satellite sites, telemedicine, Skype, and other Web-based approaches to remote service delivery. (2014, 2013, 2012)

- Raise awareness among EMA decision makers of the difficulty accessing services in the Collar Counties using mass transit. (2014)
- Conduct needs assessments as necessary to identify specific transportation needs in the regions. (2013)
- Collect and share strategies that are working across the state to eliminate transportation as a barrier to access to care and services including improving transportation and reducing the need for clients to travel a long way for services. (2013, 2012)
- Make transportation assistance a priority across regions. (2012)

Best Practices in HIV Prevention and Care

- Implement a system for identification and sharing best practices including best practices among local programs that they can share with others. (2014, 2013)
- Consider mentoring and other capacity building partnerships between larger and small organizations, well-established and newer organizations, well-funded and struggling organizations, and HIV and non-HIV organizations. (2014, 2013)
- Commit the time necessary to build individual and organizational capacity to implement best practices in HIV prevention and care. (2013)
- Take advantage of existing opportunities to keep up with the literature, such as online resources and updates from CDC, and create new opportunities such as hosting rotating local brownbag lunches where an organization is responsible for presenting best practice models or interventions and leading a discussion. (2013)

Training

- Offer more training on hot topics such as cultural competence, DEBIs/EBIs, PrEP, social media strategies, DIS, high-impact prevention, and comprehensive risk counseling and services (CRCS). (2014, 2013, 2012)
- Remove funding restrictions or other system barriers to sharing training across agencies and programs such as restrictions on who is eligible to attend. (2013, 2012)
- Implement a staff development program—assess staff training needs regularly and provide tailored training to meet identified needs. (2012)
- Ensure that HIV prevention, care, and treatment providers have the right and timely training necessary to provide high quality services or deliver complex interventions. (2013, 2012)
- Provide hands-on training, role playing, and other opportunities for staff to practice what they are learning. (2012)
- Consider using trainers from a broad range of perspectives and experience such as CBOs or local experts with knowledge of the community. (2013)
- Enhance integrated staff development and training. Train staff from different kinds of agencies, programs, and disciplines together. Share training opportunities among partners and potential partners. (2013, 2012)
- Get the word out about training opportunities through existing collaboration channels. (2012)
- Use online resources and Web-based training to reduce the cost of training and increase its availability across the state. (2012)

- Promote education and training on HIV care and prevention into the curriculum for health professionals including schools of medicine, nursing, and public health. (2014, 2012)
- Create and offer training for physicians and other health care providers on HIV care standards—in particular, for private providers who may be seeing HIV patients for the first time through ACA private insurance. (2014, 2012)

Staffing

- Create and support peer navigator positions. (2014, 2013)
- Examine budget allocations to determine if salaries are adequate to recruit and retain high quality staff—are staff compensated fairly? (2013)
- Match the knowledge, skills, and abilities of staff to their positions and the duties they are asked to perform. (2013)
- Consider the career pathway of frontline HIV/AIDS service providers and create opportunities for progression such as training for disease investigation specialist certification. (2013)
- Work to increase the availability of behavioral health providers in communities where it is difficult to access those services. (2014)

Cultural Competence

- Promote partnerships and collaboration among HIV/AIDS organizations and people of color organizations, LGBTQ organizations, faith-based organizations, immigrant and refugee centers, and other organizations with a history of successfully reaching and serving targeted populations. (2014, 2013, 2012)
- Explore the principles of cultural competence—does the program honor the full diversity of local communities including sexual and gender orientation? (2013)
- Value and reward culturally competent staff and organizations. (2013, 2012)
- Hire culturally competent staff, including people who reflect the diversity of high-risk and local communities—and ensure that all staff are able to work effectively within and across cultures. (2013, 2012)
- Provide existing staff with education and training to build their cultural competence. (2012)
- Find opportunities to support cultural competence training and resources for physicians, nurses, and other health care personnel, with special emphasis on private providers and providers not working in HIV-specialty areas. (2014)

Collaboration and Integration

- Build organizational capacity and reduce duplication through partnerships with colleague and competitor organizations. (2014, 2013)
- Model at the state level the same kind of collaboration that is needed at the local level. (2012)

- Work to break down silos that inhibit collaboration including:
 - silos between care and prevention,
 - silos among competing community partners, and
 - silos among disciplines. (2012)
- Integrate certain HIV and STI services to expand testing, get more people into care, and improve referrals, follow up, and continuity of care. (2013, 2012)
- Invest in building stronger relationships among referral sources and a community referral network—identify providers across the spectrum of health, human services, and social justice organizations and build strong relationships among referral sources and partners. (2013, 2012)
- Collaborate with the ACA insurance marketplace at all levels. Work with providers who may be seeing HIV patients with private insurance for the first time to promote HIV care standards. (2014, 2013)
- Engage with local pharmacies and pharmacists as partners and resources in the care system. (2014)
- Partner with local elected officials and community leaders to engage with school boards to create receptivity to school-based, comprehensive, developmentally appropriate sexuality and HIV education. Work with the schools and school personnel to support that, and explore replicating programs and curricula that work. (2014)
- Engage with school systems to reach young people and families. Promote school-based, comprehensive, developmentally appropriate sexuality education and offer assistance with HIV education. (2013)
- Explore replicating sexuality education programs and curricula that work. (2014)
- Work with parent organizations to get information out to parents and families. (2014)
- Get prevention messages out to high-risk populations through partnerships with organizations and venues that are already reaching and serving specific populations such as people of color, immigrants and refugees, and LGBTQ communities. (2014, 2013, 2012)
- Engage with LGBTQ organizations and community leaders to get HIV, care, prevention, and treatment messages out to the community and to engage members in HIV testing and care. (2012)
- Build cultural competence through partnerships among HIV/AIDS providers and CBOs successfully reaching and serving specific populations. (2012)
- Engage churches, pastors, church gatekeepers, and others in the faith-based community in HIV/AIDS awareness, prevention, care, and treatment services. (2014, 2013, 2012)
- Develop faith-based leaders as HIV champions. (2014)

Media and Public Awareness

- Engage with local media to get HIV information, prevention messages, and features out to the general public. (2014, 2013)
- Collaborate with the media to develop and disseminate public service announcements. (2013)
- Work to develop and support HIV champions. (2014)

- Increase the quality and extent of social media use as a tool to reach MSM, youth, and other populations with targeted HIV awareness information and messages about prevention, testing, and care. (2014, 2013)
- Explore expanding Text 2 Survive or using alternate systems to include appointment reminders and similar messages. (2013)

Stigma and Discrimination

- Build an education and advocacy mindset to combat HIV stigma and discrimination against the LGBTQ community, injection drug users, and other stigmatized populations. (2014, 2013)
- Develop advocates with the skills to be heard from within community-based organizations and among people living with HIV. (2014, 2013)
- Combat LGBTQ discrimination through education and advocacy. (2012)
- Promote LGBTQ awareness and acceptance in the schools and in other programs for youth. (2012)
- Provide/advocate for comprehensive, age-appropriate sexuality education in the schools, beginning early. (2012)
- Encourage adoption and enforcement of anti-bullying policies in the schools and other youth-serving agencies. (2012)
- Advocate for laws and policies that promote LGBTQ equality such as anti-discrimination in employment. (2012)
- Review disclosure laws and policies and amend those that create barriers to DIS (2014) or promote stigmatization (2013, 2012).

System Barriers and Opportunities

- Examine funding formulas to determine how they can be improved. (2014, 2013, 2012)
- Examine funding approaches to determine if they contribute to silos, territoriality, and unproductive competition rather than encouraging collaboration. (2013)
- Examine the grant scopes system to see if greater flexibility can contribute to meeting local community need. (2014, 2013)
- Look for ways to encourage collaboration and integration at the community level through funding approaches. (2014, 2013)
- Create real incentives that motivate organizations to collaborate and support the ones who do. (2014, 2013, 2012)
- Clarify roles and responsibilities between and among state agencies and localities. (2013)
- Explore ways to get all the voices to the table that need to be there—including local health departments and other decision makers—for important planning events such as the regional stakeholder engagement meetings. (2014)
- Collaborate to solve workforce issues including too few providers in some areas. (2013)
- Represent the needs of people living with HIV in ACA implementation and Medicaid expansion. (2014, 2013)

- Develop strategies for ensuring that private providers who may be seeing HIV-positive patients for the first time as a result of ACA implementation have access to HIV standards of care. (2014)
- Combat AIDS complacency—seek to raise the profile of HIV/AIDS as a priority issue for the State of Illinois. (2013)
- Be open to changing organizations and services to keep pace with changes in the epidemic. (2013)
- Advocate for and support comprehensive, developmentally appropriate, school-based sexuality and HIV education. (2014, 2013)
- Work with local health departments to raise their awareness of social media as an effective tool in HIV prevention and care services. Help local organizations overcome resistance to and restrictions on the use of social media strategies and approaches. (2014)

The recommendations that arose from the eight regional HIV/AIDS strategy stakeholder engagement meetings complement a multitude of other state and regional community discovery and needs assessment activities in Illinois. Together with the outcomes from those activities, they can be used to help address any persistent gaps and barriers in accessing HIV prevention, care, and treatment and help move Illinois further on the path to achieving the National HIV/AIDS Strategy goals of reducing new HIV infections, increasing linkage to care and positive health outcomes for people living with HIV, and eliminating health disparities. Success will continue to require a comprehensive, coordinated effort by stakeholders across the community and across programs—federal, State, and local—including key HIV leaders, government and non-governmental entities, HIV clinical and prevention programs, support services, corrections, mental health and substance use, housing, and academia, among others.

Appendices

- Appendix A: Acronym List
- Appendix B: HIV Planning Group Protocol for 2013-2014 HIV Engagement Meetings—Final Draft
- Appendix C: Combined Participants—2012 HIV/AIDS Strategy Stakeholder Engagement Meetings
- Appendix D: Combined Participants—2013 HIV/AIDS Strategy Stakeholder Engagement Meetings
- Appendix E: The HIV Strategy Stakeholder Engagement Meeting Roundtable Discussion Questions—Final Draft
- Appendix F: The 2014 HIV Strategy Stakeholder Engagement Meeting Agenda Template—Final Draft
- Appendix G: Region Two, Five, and Seven Combined Meeting Notes

Appendix A

Acronym List

AAARA	African American AIDS Response Act
ACA	Affordable Care Act
AIDS	Acquired Immunodeficiency Syndrome
AMA	American Medical Association
CAHISC	Chicago Area HIV Integrated Services Council
CAWC	Connections for Abused Women and Their Children
CCDPH	Cook County Department of Public Health
CDC	Centers for Disease Control and Prevention
CDPH	Chicago Department of Public Health
CEU	Continuing Education Unit
CHC	Community Health Center
CME	Continuing Medical Education
DASH	Division of Adolescent and School Health, CDC
DCFS	Department of Child and Family Services
DEBI	Diffusion of Effective Behavioral Interventions
DHS	Department of Human Services
DIS	Disease Intervention Services
DOC	Department of Corrections
EBI	Effective Behavioral Intervention
EMR	Electronic Medical Record
ESHE	Exemplary Sexual Health Education
EMA	Eligible Metropolitan Area
FQHC	Federally Qualified Health Center
HCV	Hepatitis C Virus
HD	Health Department
HHS	U.S. Department of Health and Human Services
HIHAC	Heart of Illinois HIV/AIDS Center
HIV	Human Immunodeficiency Virus
HMO	Health Maintenance Organization
HOPWA	Housing Opportunities for Persons with AIDS
HUD	U.S. Department of Housing and Urban Development
IDFPR	Illinois Department of Financial & Professional Regulation
IDOC	Illinois Department of Corrections
IDU	Injection Drug Use or Injection Drug User
IHAS	Illinois HIV/AIDS Strategy
IATF	Illinois Interagency AIDS Task Force
IDPH	Illinois Department of Public Health (Department)
ILHPG	Illinois HIV Planning Group
ISBE	Illinois State Board of Education
LGBTQ	Lesbian, Gay, Bisexual, Transgender, and Questioning

LTC	Linkages to Care
MATEC	Midwest AIDS Training and Education Center
MSM	Men Who Have Sex with Men
NAACP	National Association for the Advancement of Colored People
NHAS	National HIV/AIDS Strategy
NIPHC	Northern Illinois Public Health Consortium
nPEP	Non-Occupational Post-Exposure Prophylaxis
OB/GYN	Obstetrics/Gynecology or Obstetrician/Gynecologist
PACPI	Pediatric AIDS Chicago Prevention Initiative
PCSI	Program Collaboration and Service Integration
PEP	Post-Exposure Prophylaxis
PPO	Preferred Provider Organization
PrEP	Pre-Exposure Prophylaxis
PSA	Public Service Announcement or Public Service Advertisement
PTA	Parent Teacher Association (National PTA = National Congress of Parents and Teachers)
PWHIV	People with HIV
RFA	Request for Applications
RIG	Regional Implementation Group
RW	Ryan White
SES	Socioeconomic Status
SIU	Southern Illinois University Carbondale
SSE	Safe Supportive Environment
STD	Sexually Transmitted Disease
STI	Sexually Transmitted Infection
TB	Tuberculosis
USPSTF	U.S. Preventive Services Task Force

Appendix B

HIV Planning Group (ILHPG) Protocol for 2013-2014 HIV Engagement Meetings (Final Draft)

1. A workgroup, composed of the IDPH PCPG Coordinator, the PCPG Community Co-Chair, and members of the PCPG Evaluation Committee, was formed to develop the protocol, discussion questions, objectives, and procedures to be used in planning and conducting the July and August 2012 stakeholder engagement meetings. The PCPG Coordinator developed a first draft of the documents, utilizing as a guide the protocol and discussion questions that had been developed by the workgroup planning the September 14, 2012 Southern IL NHAS Meeting in Collinsville. Members of this workgroup then participated by conference calls to develop, finalize, and approve all documents to be used in the stakeholder engagement meetings. This included ensuring that the discussion questions would meet the objectives of the meeting and were open-ended questions capable of qualitative analysis.
2. A Committee, composed of the IDPH ILHPG (previously PCPG) Coordinator, the ILHPG Community Co-Chair, and members of the ILHPG Evaluation Committee, was formed to develop the protocol, discussion questions, objectives, and procedures to be used in planning and conducting the July and August 2012 engagement meetings. The ILHPG Coordinator developed a first draft of the documents, utilizing as a guide the protocol and discussion questions that had been developed by the workgroup planning the September 14, 2012 Southern IL NHAS Meeting in Collinsville. Members of this workgroup then participated by conference calls to develop, finalize, and approve all documents to be used in the engagement meetings. This included ensuring that the discussion questions would meet the objectives of the meeting and were open-ended questions capable of qualitative analysis.
3. The following are the overall goals of the meeting(s):
 - A. OVERALL MEETING GOAL 1:** To achieve a more coordinated response to HIV by engaging key community stakeholders and increasing collaboration and coordination among HIV programs.
 - B. OVERALL MEETING GOAL 2:** To increase community stakeholders' awareness and understanding of the National and Illinois HIV/AIDS Strategies and how that translates to state and local HIV care, treatment, and prevention programs
4. The meeting(s) will typically be scheduled from 10-4:00 p.m., but the time may be lengthened if there are more than 40 participants. The agenda for the meeting will include a Working Lunch, an Introduction of all participants, an Overview of the Purpose of the Meeting, Presentations on the Regional epidemic (to include a demographic breakdown of HIV incidence, prevalence, and late diagnosis), on the NHAS/IHAS, and on the ILHPG HIV Engagement Plan as an example of how the NHAS/IHAS translates down to the state/local programmatic level.

5. Five objectives that align with the goals of the NHAS/IHAS have been developed. A minimum of two discussion questions will be developed to address each objective. Time permitting, all objectives and discussion questions will be discussed. The ILHPG may limit the objectives and questions, however, if time does not permit discussion of all.
 - A. **OBJECTIVE 1:** To engage local health departments, other HIV programs (care, treatment, and prevention), and other key stakeholders in HIV planning.
 - B. **OBJECTIVE 2:** To identify opportunities for collaboration and coordination across all HIV programs, statewide and local.
 - C. **OBJECTIVE 3:** To develop strategies to reduce new HIV infections and reduce HIV-related disparities and health inequities.
 - D. **OBJECTIVE 4:** To increase linkage and access to care and improve health outcomes for people living with HIV.
 - E. **OBJECTIVE 5:** To identify ways to mitigate the impact of stigma and discrimination on HIV care, treatment, and prevention.
6. The ILHPG will invite participants in the engagement meetings by reaching out through the Regional Care and Prevention Lead Agents to provide a listing of HIV care and prevention providers in the region. In addition to these providers, representatives from the following agencies in the area will be invited: HIV Program Directors, and STD Clinic/DIS staff from Local Health Departments; staff from any HIV Housing facilities; staff from substance abuse and mental health agencies; Discharge planners at correctional facilities; Quality of Life funded grantees, Centers for Minority Health Services grantees; African-American AIDS Response Act grantees; and client representatives. ILHPG members from the respective region and the ILHPG Co-Chairs will be invited to participate in each meeting.
7. The IDPH ILHPG Coordinator and Co-Chair will attend all focus groups and provide needed support. The focus groups will be facilitated by the ILHPG Coordinator. The regional HIV Epidemic presentation will be provided by a representative from the IDPH HIV/AIDS Section Surveillance Unit. Mildred Williamson, the IDPH HIV/AIDS Section Chief, will present on the NHAS and the IHAS. Janet Nuss and/or the current ILHPG Community Co-Chair will present on the ILHPG HIV Engagement Plan.
8. The Evaluation plan includes the following: IDPH staff, ILHPG members, and other regional participants, as needed, will be assigned to breakout groups and will be asked to take notes and to facilitate discussion when the larger group breaks out into smaller groups in the afternoon for roundtable discussion. Notes will be compiled by the Evaluation Committee or the IDPH Community Planning intern, typed and sent to Dr. Ma who will analyze and develop a report for each engagement meeting, using qualitative analysis. Responses to each objective and corresponding questions will be

evaluated using qualitative, generalized, descriptive analysis. These reports will be completed by December 2013, distributed to the participants in the regional meetings, disseminated to the Regional Care and Prevention Lead Agents for distribution to their providers, and posted on the www.ilpcpg.org website.

9. Each engagement meeting will be limited to 40-60 participants, total.
10. Participants will be provided with a working lunch.
11. Participants will be asked to complete a participant profile form at the end of the meeting. Non-ILHPG member representatives from agencies not funded by IDPH and/or not able to claim travel reimbursements from their employer will be provided with a \$25 gas at the end of the meeting to help defray the cost of their transportation and participation and as thanks for their participation.

Guidelines for Facilitators:

Jamie and/or Janet will review with the entire group:

1. Designate which tables will be included in which breakout group.
2. Designate a facilitator and a recorder for each group. The recorder must be able to take comprehensive notes and write legibly. The recorded notes will be handed in at the end of the meeting.
3. Review the timeline established for discussion of each objectives and set of discussion questions with the group.
4. Review the norms for respectful discussion – listen to others; be respectful of ideas and comments of others that may be different from your own; do not monopolize the discussion.
5. Recognize that there are several group discussions going on simultaneously. Try to keep the noise level within your group at a level that does not disturb nearby groups.

Facilitator Instructions:

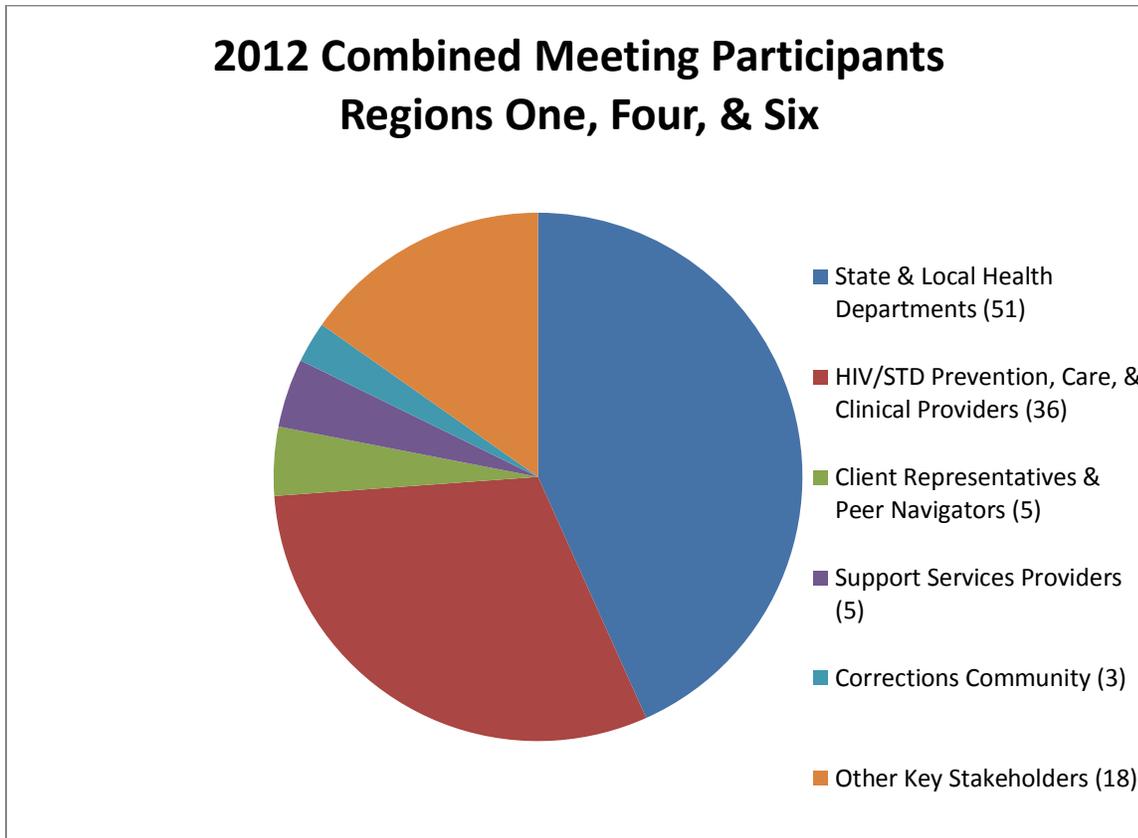
1. Review the objective. Read the discussion question. The questions are all open-ended to encourage attendees to relate their experiences, recommendations, and educated opinions.
2. Guide, do not lead, the discussion. Your opinions are valuable and you can state your opinions, but don't monopolize the discussion or try to lead the discussion in a particular direction.
3. Keep the discussion focused on the topic at hand. Redirect participants if they start to go off on a tangent.
4. Ensure whoever is speaking is speaking loud enough for the recorder to hear what is being said.
5. Do not let other members in the group dominate the discussion.
6. Reinforce the importance of each person's input and encourage people who are not speaking up to take part in the discussion.

7. Remember that it takes time for a group to develop trust. Be patient and encourage participants to enjoy the discussion.
8. Thank you so much!!!

08/12/2013

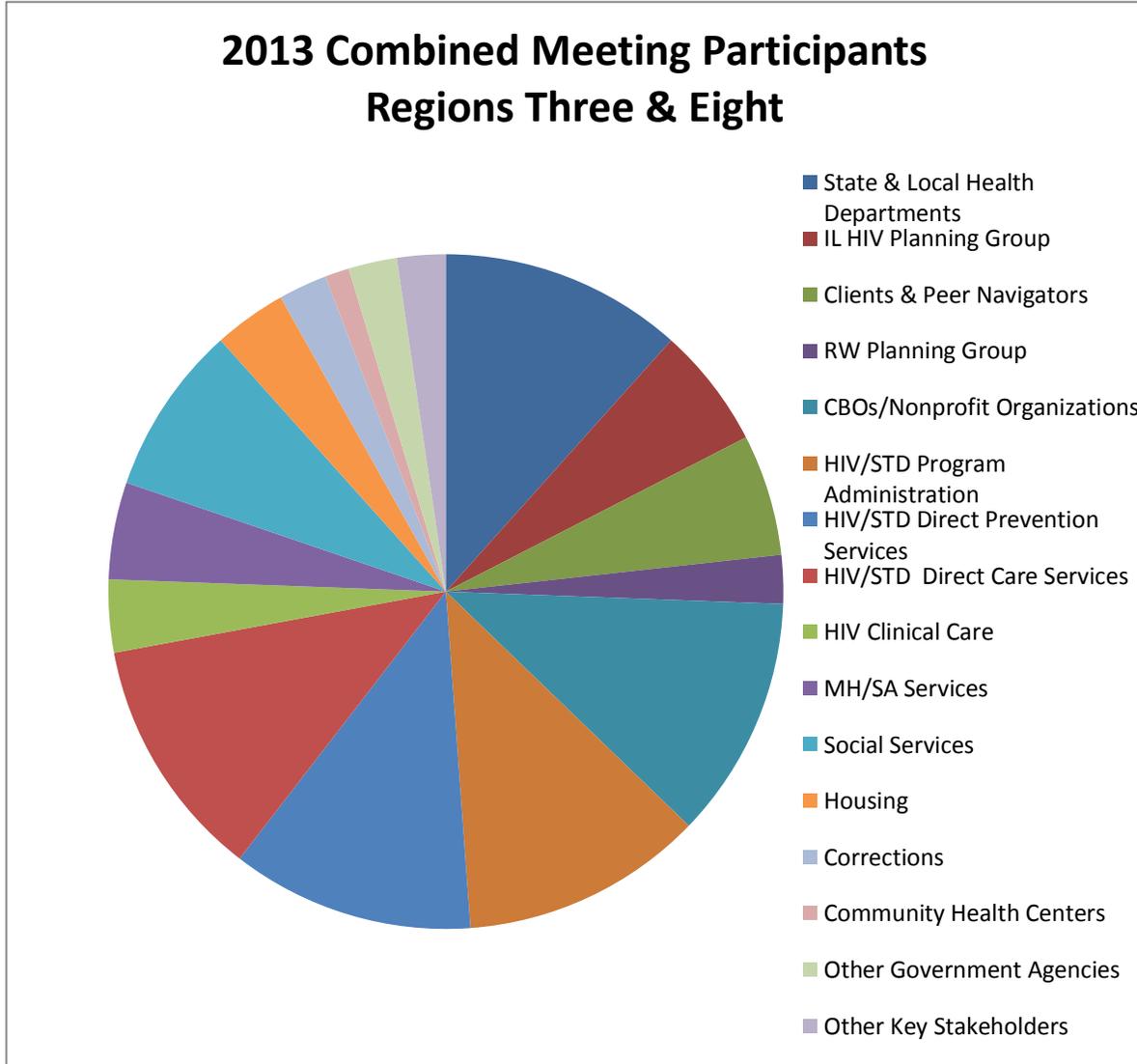
Appendix C

Combined Participants—2012 HIV Strategy Stakeholder Engagement Meetings



Appendix D

Combined Participants—2013 HIV Strategy Stakeholder Engagement Meetings



Appendix E

HIV Strategy Stakeholder Engagement Meeting Roundtable Discussion Questions (Final Draft)

OVERALL MEETING GOAL 1: To achieve a more coordinated response to HIV by engaging key community stakeholders and increasing collaboration and coordination among HIV programs

OVERALL MEETING GOAL 2: To increase community stakeholders' awareness and understanding of the National and Illinois HIV/AIDS Strategies and how that translates to state and local HIV care, treatment, and prevention programs

(20 MINUTES) **OBJECTIVE 1:** To engage local health departments, other HIV programs (care, treatment, and prevention), and other key stakeholders in HIV planning.

Question 1: The strategy impels us to engage entities from HIV prevention, care, and treatment; STD, TB, and viral hepatitis; mental health and substance use; housing; related supportive services; and other key stakeholders in HIV planning.

1.1 What other entities need to be engaged in this process and at what level (referral, planning) should they be engaged?

1.2 What would you like to see come out of these planning efforts?

(20 MINUTES) **OBJECTIVE 2:** To identify opportunities for collaboration and coordination across all HIV programs, statewide and local.

Question 2: The strategy impels us to increase coordination and collaboration across HIV prevention, care, and treatment; STD, TB, and viral hepatitis services; mental health and substance use services; housing and other supportive services.

2.1 What potential opportunities for collaboration and coordination of activities do you see?

2.2 What are the challenges or barriers to this?

(30 MINUTES) **OBJECTIVE 3:** To develop strategies to reduce new HIV infections and reduce HIV-related disparities and health inequities.

Question 3: The strategy says three critical steps we must take to reduce HIV infection are:

1. Intensify prevention efforts in communities where HIV is most heavily concentrated.
2. Expand targeted efforts to prevent infections using a combination of effective, evidence-based approaches.
3. Educate all Americans about the threat of HIV and how to prevent it.

- 3.1 How do we balance the demand to intensify targeted interventions for the most impacted populations and the need to provide general education and prevention services?
- 3.2 Federal and State HIV prevention funds for Illinois were cut this year and may be cut in future years. Knowing that, what recommendations can you provide the State about ways to best intensify prevention efforts in communities where HIV is most concentrated?
- 3.3 What HIV health inequities do you see and what strategies can you suggest to address them?

(30 MINUTES) **OBJECTIVE 4:** To increase linkage and access to care and improve health outcomes for people living with HIV.

Question 4: Comprehensive prevention services (including partner services) for persons living with HIV are a priority of the strategy.

- 4.1 What needs to be done to ensure HIV positive individuals have access to prevention, care, treatment, and supportive services to decrease the risk of HIV transmission to their partners and retain them in care?
- 4.2 What does your organization need to incorporate prevention for HIV positives into its array of services?
- 4.3 What are some challenges or barriers your organizations face in providing comprehensive prevention for positives services?

(20 MINUTES) **OBJECTIVE 5:** To identify ways to mitigate the impact of stigma and discrimination on HIV care, treatment, and prevention.

Question 5: In this region, the latest epidemiology data suggest the following: *(Note: Include a description of the current regional HIV epidemiologic data that is to be revised for each region):*

- 5.1 What does your organization need to implement effective, appropriate interventions for this population?
- 5.2 What needs to be done at the structural level (policies, laws, and infrastructure) to reduce stigma and to ensure clients have access to services that are culturally appropriate?

Appendix F

Region _____ HIV/AIDS Strategy 2014 Stakeholders Engagement Meeting Agenda (Final Draft)

- 10:00-10:30 p.m. Welcome, Introductions, Meeting Purpose and IDPH HIV Engagement Strategy**
- *Janet Nuss-IDPH HIV-AIDS Section Prevention Planning Coordinator and ILHPG Co-Chair*
 - *Michael Maginn, ILHPG Community Co-Chair*
- 10:30 – 11:00 p.m. National and Illinois HIV/AIDS (NHAS/IHAS) Strategies**
Mildred Williamson, IDPH HIV-AIDS Section Chief
- 11:00 - 11:45 p.m. HIV Epidemic in the Region**
Cheryl Ward (or designee) – IDPH HIV-AIDS Section Surveillance Administrator
- 11:45 – 12:45 p.m. Lunch Break**
- 12:45 – 1:00 p.m. Roundtable Instructions**
- 1:00 - 3:00 p.m. Facilitated Roundtable Discussions**
- *Goal: Identify community challenges, successes, and strategies in implementing the concepts of the NHAS/IHAS, focusing most on opportunities for collaboration and coordination at all levels*
 - *Participants will break out into groups. Facilitators (IDPH staff and/or assigned ILHPG members) at each table will lead Discussion Questions based on the NHAS/IHAS Objectives*
- 3:00 - 4:00 p.m. Report Out, Closing Discussion & Next Steps**
- 4:00 p.m. Adjourn**

Appendix G

Compiled Notes—Roundtable Discussion Questions

Region Two—Heart of Illinois 2014 HIV Engagement Meeting
May 9, 2014

Question 1: The strategy impels us to engage entities from HIV prevention, care, and treatment; STD, TB, and viral hepatitis; mental health and substance use; housing; related supportive services; and other key stakeholders in HIV planning.

1.1 What other entities need to be engaged in this process and at what level (referral, planning) should they be engaged?

Group One

- School system personnel to engage in the planning process
- List of 100 invitees—reach out to them again to see how they can be engaged
- Mental health and human services should be engaged
- Medical providers, medical and nursing systems
 - Medical facility providers
 - Residency programs, as part of rotations—need to get on the agenda a year in advance
 - Offer CEUs
 - Arrange timing to accommodate their routines
 - Attend their meetings (doctors, residents, provider groups)
 - Housing groups/housing administration need to be at the table; look at securing board meetings and then getting involved or on the agenda for their board meetings
 - Reach out to entities that do training, work with them to do community/provider engagement
 - Explore getting Risk Reduction Training, such as Ask, Screen, Intervene (ASI) into providers' curricula
 - Get HIV into the curricula of school sex education classes
 - United Way is an organization to reach out to

Group Two

- State agencies are in silos, so we need to break down the silos among the agencies that help the disadvantaged and needy; they need to be identified and engaged
- Churches have so much influence
- Continuation of care is a collaboration for multiple organizations—Township Relief Office, First Methodist Church, Prairie State Legal Services (for low-income, HIV-positive clients), university housing

Group Three

- Corrections System—juvenile justice, jails, prisons (Illinois River Correctional Center, Federal Correctional Institution Pekin, etc.)

- Education institutions—junior colleges, medical schools
- Health centers
- Heart of Illinois 2-1-1 line (United Way)
- All entities signing persons up for medical insurance
- Medical clinics and hospitals
- Planned Parenthood
- Human services agencies (social workers, etc.)
- Cultural groups (NAACP, Hispanic advocacy groups)
- Help by providing education, condoms, referrals
- Utilize businesses/marketing students to conduct projects

Group Four

- Department of Children and Family Services (DCFS)
- County health departments are not all represented
- Hospitals are not represented; there are 15 in the county
- Pediatricians
- Federally qualified health centers (FQHCs)
- Housing providers
- Clergy
- Advocates
- Law enforcement including parole and probation
- School districts
- Veterans, veterans family support agencies
- Vocational rehabilitation
- Mental health
- Lesbian, bisexual, gay, transgender, and questioning (LGBTQ) support agencies
- City Councils, county supervisors
- Minority-based organizations (Hispanic Caucus, NAACP)
- Discussion (about the meeting participation): personal invitations make a difference, the invitation was linked to one person and could not be forwarded, there may be concern that it is an all-day meeting, there may be travel restrictions for local health departments

1.2 What would you like to see come out of these planning efforts?

Group One

- Go to parents and PTA—start out planning with parent groups to get information and education out the families
- Need more awareness of the resources/referrals for the community
- Pharmacist who is new to the area wants to get educationally aware of the experts in the area to make referrals for clients
- Want to see how we look more into gaps into care and how to work together to begin to fill the gaps.
- Illinois Ryan White HIV Advisory meetings have been helpful to see how systems network

- It would be useful to engage case management in networking with other systems (prevention, providers, corrections)
- Need more ways for providers of services get together to share resources and ways to work together—maybe creating a listserv to allow providers to ask questions and learn from each other
- Need to ensure outreach and engagement of those working in the jail system or the Department of Corrections
- Regions should send invites out to find those in correctional facilities who are willing to be representatives to a larger planning group
- Timing is an issue on how to get them to the table
- Work more closely with school health programs and staff who work in the schools
- Illinois State Board of Education (ISBE) plays a key role; see how they get information down the chain to field workers—how are they providing school information on HIV
- Look at when schools are doing testing days, when high school clinics are doing testing, when reproductive health clinics are providing testing
- The Reproductive Planning Committee is a great resource in the region
- Do HIV 101 instruction for nursing students in schools and for school nurses, also look into women’s health classes in schools and universities
- Population health venues (health fairs, conferences) are a good way to get HIV messages and education in front of people

Group Two

- Education at all levels to engage and motivate people; education may identify patterns we may not know about—for instance, what kept people from coming to this event
- Agencies may not necessarily understand how they relate and why their involvement in HIV planning is needed
- We see the same organizations at these meetings—maybe make it mandatory that all agencies that receive state funding attend
- Use community organizations to mobilize the community
- Help organizations take their blinders off—is there a perceived risk to getting involved
- What efforts are being made to educate others entities and what else can be done
- Is there training available for people “on the ground”
- Broaden our forces to educate the general population (this may help reduce stigma); develop a video presentation that could be put on YouTube; use social media, PSAs and TV

Group Three

- There are many services in this area, but coordination is needed
- A comprehensive referral listing and resource guide
- Communication and collaboration to promote interactions and reduce duplication of services
- More interaction between corrections and local agencies
- An email listing when seeking funding sources and/or a method of communicating information on newly released funding sources—there may be a version of this from the federal Department of Health and Human Services (HHS)
- A way of sharing upcoming events (health fairs, Summits of Hope, etc.)
- Help distributing the HHS/Walgreens flu vaccination vouchers to needy populations

Group Four

- Stakeholders playing better together
- Action!—more than talking, focused and funded action, even if small
- Targeted marketing campaigns
- Work to help people think about and understand the relationship with local determinants and disproportionate rates; for example, use the resources, such as the epidemiologic maps, as an overlay to determine what the correlation is with local unemployment
- Provide opportunities for student nurses looking for placements/places to do nursing rotations

Question 2: The strategy impels us to increase coordination and collaboration across HIV prevention, care, and treatment; STD, TB, and viral hepatitis services; mental health and substance use services; housing and other supportive services.

2.1 What potential opportunities for collaboration and coordination of activities do you see?

Group One

- OFS Healthcare reaches the region as a whole, and the OSF nursing system should be looked into for ways to network and get training and education opportunities in the system
- Be part of community health outreach in the community; look for opportunities for community projects; use medical students who are not in residency and tap into their need for projects they can complete and take over for a grade (also good for exposure)

Group Two

- Incorporate Hepatitis C education and outreach with HIV
- Public access TV will produce educational programs on demand across the state; use YouTube and churches
- Build a coalition of agencies in the area and provide counseling and testing services at churches during events

Group Three

- More Summits of Hope
- National/regional testing event
- World AIDS Day
- Other corrections events that might be opportunities
- DCFS
- Social services agencies
- Work with the Peoria Continuum of Care
- Fairs
- Integrating events to reach overlaps in populations as a way of reducing duplication of scarce resources

Group Four

- There are LGBTQ services in the region and an opportunity there for growth and capacity building

- Bradley University has an affinity group; this is a place to start building relationships
- ACORN group has a breakfast annually, another starting place
- Some collaboration is being done with Peoria Proud; this is primarily a social meeting right now
- Consumer peers
- Community action agencies, rent assistance, utility assistance are opportunities to collaborate
- Reproductive health groups
- Faith-based working groups
- Regional superintendents—get on their meeting agenda
- The local school district is participating with the ISBE on the DASH grant-collaboration opportunity; this will involve other community organizations
- Tazewell County School District is working with parents
- DCFS for children aging out of the system—there is in-network collaboration
- Psych rotation is an opportunity with Heart of Illinois HIV Center (HIHAC)
- Get Planned Parenthood at the table; they serve the target population
- Educate boards of health—don't assume they know
- 211, Community Social Service has a resource list
- Illinois Department of Financial and Professional Regulations could require HIV education and training for RNs/LPNs, etc. for license renewal
- Pull leadership of small groups into an interagency group
- Hold a follow up discussion from the group
- Can DASH grant activities and the Tazewell County School District program be replicated in the Region
- Local participants don't have a good sense of who's doing what in the region

2.2 What are the challenges or barriers to this collaboration and coordination?

Group One

- Look for ways to network with local pharmacies (Walgreens/CVS) for educational opportunities
- They are under-tapped partners
- Reach out to see how they could enhance the work we are doing in communities
- Be sure to not offend them by going in to their communities and doing education without reaching out to them
- The Walgreen's representative discussed the importance of specialty pharmacies in the area that serve a targeted disease set
- Pharmacies of excellence—specialty pharmacies more trained in certain drugs than the average pharmacist
- Specialty pharmacists can work to transition clients, once secure in their treatment, to a pharmacy located closer to the client
- Look into mail services, even from the specialty pharmacy
- Need to get information out about centers of excellence, but it can be a double edge sword—if someplace is identified as an HIV center, clients may feel stigmatized and fear being identified as HIV positive

- The balance is between the press releases and serving clients
- Stigma could be addressed by having centers of excellence focus on all chronic diseases in addition to HIV—getting others to see HIV as just another chronic disease
- Two local centers of excellence here—Peoria Heights is an HIV center; Sterling Heights works with other diseases; we need people in these centers to be passionate about their work

Group Two

- Lack of funding for Hepatitis C testing, care, and education
- People don't care about the topic; everyone is very busy, with competing demands for time and energy, especially when agencies don't see the connection to their mission
- The distance between major populations, communities, and services—drain on resources, lots of time required—not knowing exactly where to target services
- Cultural and language barriers
- Religious beliefs
- Transportation between communities
- Limited hours of service

Group Three

- Sex offender populations often cannot receive services—using probation/parole officers could help
- Transportation issues are barriers
- Stigma is associated with not accessing services
- Lack of funding for smaller agencies and many needed services
- New healthcare system (ACA) may have an impact on services (availability and access)
- Ignorance of services and lack of awareness
- Many clinics in the area do not perform some testing labs

Group Four

- Lack of knowledge about what's out there in the community
- Lack of money
- Distance-isolated communities—rural and remote
- Getting on the agenda of the meetings of some the groups (faith based, City Council, etc.)
- High case loads, travel time, limited time to be out of the office
- Silos, some based on funding streams; mental health, substance abuse, public health, education—each has its own agenda and meetings
- Groups are territorial
- Legal issues between hospitals and pending lawsuit locally
- Social norms, stigma
- Unmet needs, resources
- Ability to share information across websites
- Electronic referrals may hinder real time referrals; referral process needs to change

Question 3: The strategy says three critical steps we must take to reduce HIV infection are: (1) intensify prevention efforts in communities where HIV is most heavily concentrated; (2) expand targeted efforts to prevent infections using a combination of effective, evidence-based approaches; and (3) educate all Americans about the threat of HIV and how to prevent it.

3.1 How do we balance the demand to intensify targeted interventions for the most impacted populations and the need to provide general education and prevention services?

Group One

- HIV education in Peoria starts in 8th grade
- General HIV education starts at this grade then starts again in high school with all the sexually transmitted diseases
- More schools have been asking about more STD education
- Schools pay for this education or it is funded through United Way grants
- Working with local health departments—getting introduced at local meetings especially with rural areas; local health departments know the gaps and the resources in the area for public health outreach, and they know what groups are open and receptive to listening to the topic of HIV
- Social media opportunities may be ways to reach out to areas that may not be targeted and to work around those who do not want HIV talked about in their areas
- Use nontraditional models for outreach outside the local areas
- Use colleges and universities to launch initiatives that the local health department is unable to do; graduate students are a great untapped resources, and they often seek relationships with public and private agencies for student internships and projects

Group Two

- Only paying for targeted populations is an issue
- What happens with lower risk clients who need testing and may be lost in transition
- This is further complicated by service requirements
- People don't necessary disclose risk; we may need different methods to reach different populations
- Effective advertising is needed to get HIV prevention education and awareness messages out there every day

Group Three

- Increase health education in schools—stress that HIV is not a gay disease, and dispel myths that the medicine doesn't make HIV an easy disease
- Stress the need to get tested even without symptoms
- There may be a generational issue; the control of the pandemic may have led younger generations not to fear HIV
- Talk more about sexual risk behaviors

Group Four

- Reproductive health for the entire area

- Use the zip codes with highest rates for targeted interventions and messaging along with general messaging for the county; strategize for reaching the most disparate populations first
- Using regional superintendents and involving education will make spreading the word easier
- Make HIV education a robust part of education requirements for doctors; third year med students do a rotation through HIHAC
- The U.S. Public Health Task Force gave HIV screening an “A” grade, and the ACA deems HIV screening to be an essential health benefit; do healthcare providers know this
- Establish more venues for routine screening

3.2 Federal and State HIV prevention funds for Illinois were cut this year and may be cut in future years. Knowing that, what recommendations can you provide the State about ways to best intensify prevention efforts in communities where HIV is most concentrated?

Group One

- As long as public health tiptoes around the topics of sex education and HIV education, it promotes stigma; we need to bring this out in the open as we do for any other chronic disease outreach

Group Two

- Collaborations and partnerships are needed, but people are territorial and fighting for funds; be more thoughtful about how we award funding; funding that is depreciated may encourage collaboration
- Social media should be used to locate and educate high-risk populations
- Use extra money from fee for service for advertising; even low income people with few resources are accessing social media

Group Three

- Use younger people, not older people, for prevention efforts targeting youth
- Use appropriate jargon and clarify the language so that it is understood by the population (younger and older generations use different words and jargon)
- Agencies must work together
- Use social media to reach younger populations; high schools and universities could use this to advertise testing days
- Use scan codes for information instead of brochures
- Combining efforts

Group Four

- Educate all at a younger age to shape social norms; for example, make comprehensive science based sex education required in all schools in the state
- Chicago high schools are involved in the condom campaign
- Opt-out HIV testing for all populations
- Remove classifications, labels, and targeting that creates barriers
- Have the Illinois Department of Financial and Professional Regulation require HIV training for professionals’ license renewal

3.3 What HIV health inequities do you see and what strategies can you suggest to address them?

Group One

- Look at HIV like you look at other chronic diseases—then stigma goes away
- Look at ways we create stigma among our children and our communities
- Need to work with local faith-based partners
- Have them network within their programs that are already developed to promote more HIV education
- Need to start the conversations with local pastors
- Join interfaith organizations
- There is a belief that there are opportunities to reach out to faith-based community organizations, but you cannot be fearful of reaching out
- Need to start with some of the younger pastors
- It is about how you find ways to educate and train the pastoral community
- HIV is not talked about much anymore, but it is still an issue that needs to be addressed
- Help to get local people who are HIV positive to be leaders in their community and address schools or other community events about what it is to have HIV; make it personal and let everyone know the faces of HIV

Group Two

- The increasing proportion of HIV among youth and African Americans needs to be addressed
- There are actually young people who want to be HIV positive—sense of fatalism
- There are inequalities in prescribing and the ability to access PrEP and nPEP
- When addicts are sick and need a fix, HIV is not on their minds; they need to be educated about PrEP
- Provide clinicians training on PrEP and nPEP, and offer CEUs for education sessions for physicians

Group Three

- The black MSM population with low socioeconomic (SES) status and low education level is most impacted
- There is a low level of health literacy in low SES populations
- Provide job training to increase stability and the ability to increase their status in life
- Mental health treatment, substance abuse treatment
- Case managers need training to increase their basic knowledge of mental health and substance abuse issues
- Increase coverage for dental health services of clients, which will increase their self-esteem

Group Four

- Stigma for HIV-positive minorities causes inequity by affecting the number of minorities who stay in care services and reach undetectable viral loads

- There are no organizational boards in the local area with 51 percent African American board membership for the African American AIDS Response Act (AAARA) funds—too little money has been the community response—partner with those that do have the required board composition
- Get an HIV agenda established; is the African American community aware of the data on disparities in their communities; there are venues to provide the information and raise awareness in the communities
- Overlay data in minority communities with other data such as unemployment, STD rates, housing, teen pregnancy, and incarceration to raise awareness and get a complete picture
- There is a belief—“no symptoms, no problem”

Question 4: Comprehensive prevention services (including partner services) for persons living with HIV are a priority of the strategy.

4.1 What needs to be done to ensure HIV-positive individuals have access to prevention, care, treatment, and supportive services to decrease the risk of HIV transmission to their partners and retain them in care?

Group One

- Seems there are fewer condoms available; even though people know they are free through the health department, the health departments cannot get them in the numbers they did in the past
- Work with local fraternities to help with educational and fundraiser opportunities for HIV organizations
- Target drag shows, and speak to the audience or do HIV education during intermissions; this is an opportunity to correct things people may have erroneously been taught in sex education about HIV risk, treatment, and transmission pathways

Group Two

- Education of providers, collaboration, and care providers should include more on treatment adherence, peer support, retention in care, and protection of confidentiality

Group Three

- Identify clients diagnosed but not in care and identify clients who have been lost to care
- Use “retention in care” workers
- Communicate referrals consistently with medication providers to enhance medication follow up and adherence
- Focus on viral load suppression
- Build relationships with medical providers to increase the communication between them and their patients about treatment adherence, drug tolerance, and discussion of side effects
- Prevention refers newly diagnosed clients to care but does not get feedback from the case managers so they know that the client has been enrolled in and is receiving care

Group Four

- Take services to the mobile units and satellite offices
- Link with general services to reduce stigma, one-stop shops

4.2 What does your organization need to incorporate prevention for HIV positives into its array of services?

Group One (no responses)

Group Two

- More presentations—invite outside speakers to keep awareness of HIV issues and trends current
- Broader HIV education across the organization—educate all staff on culture sensitivity, referral, partnerships, creating relationships
- Clients can be assisted with multiple issues through Legal Aid

Group Three

- All clients need to have a basic knowledge of HIV/AIDS
- Clients need to know where to go to get tested and that it is free; they will pass that information on to their peers and their partners
- Communicate the need for clients to identify partners
- Providers need to know their ability to test outside of grant scopes so they don't feel they have to turn people away

Group Four

- More collaboration—Central Illinois FRIENDS of People with AIDS would like a relationship with HIHAC
- Is there support for sero-discordant couples; that is considered prevention
- Capacity building and technical assistance
- Pairing of medical professional and peers in terms of co-facilitation
- Core training for providers

4.3 What are some challenges or barriers your organizations face in providing comprehensive prevention for positives services?

Group One (no responses)

Group Two

- Limited funding is a barrier as well as the bureaucracy around receiving funding
- Prevention for positives sometimes seems like a low priority; clients are often in multiple life crises, are preoccupied with survival, and are dealing with issues such as addictions and mental health

Group Three

- Grant guidelines and requirements
- Inability to deliver condoms in schools
- Schools limit discussion on sex
- Collaborations
- Limited funding and funding restrictions

Group Four

- Stigma—a large issue in general
- Health literacy in the patient population
- Need for capacity-building services

Question 5: To identify ways to mitigate the impact of stigma and discrimination on HIV care, treatment, and prevention.

There were 188 new cases of HIV infection diagnosed in Region Two between 2008 and 2012. This figure represents an average of 37 cases each year. There were 25% fewer cases diagnosed in 2012 compared to 2008 (40 cases in 2008, and 30 cases in 2012). Illinois experienced a 6% decrease in the number of new cases in this same period. The proportion of new cases that were male fluctuated between 2008 and 2012. In 2008, 60% (N=24) of all new cases were male. The proportion of new infections diagnosed among males increased to 90% (N=37) in 2010, and, by 2012, 83% (N=24) of all new cases were diagnosed among males. Overall, males represented 80% (N=150) of all new HIV diagnoses between 2008 and 2012.

The proportion of new cases diagnosed among blacks increased from 35% (N=14) in 2008 to 60% (N=18) in 2012. Blacks and whites accounted for nearly equal proportions of all new cases diagnosed between 2008 and 2012 (45% among each group, on average). Hispanics represented 4% (N=8) of all new HIV infections diagnosed between 2008 and 2012.

The proportion of new infections diagnosed among persons in the 20-29 age category increased from 30% (N=12) in 2008 to 37% (N=11) in 2012. In 2011, an unprecedented 45% (N=14) of all new infections occurred among 20-29 year-olds. Overall, 37% (N=69) of people diagnosed between 2008-2012 were in the 20-29 age category at the time of diagnosis, followed by 40-49 year-olds (18%) and 30-39 year-olds (16%).

Men who have sex with men (MSM)—particularly white MSM—represent a significant proportion of HIV new infections. MSM accounted for 63% of new infection between 2008 and 2012 (N=99) and 70% of new infections in 2012 (N=16) (among all cases with a reported risk). White MSM accounted for 52% (N=51) of all infections diagnosed among MSM between 2008 and 2012, followed by blacks (41%, N=41) and all other racial/ethnic categories (7%, N=7). There has been an increase in the proportion of new infections among MSM that are black—blacks represented 33% of all new infections among MSM in 2008 and 69% of all new infections among MSM in 2012. Between 2008 and 2012, heterosexual contact was attributed to 84% (N=27) of all new infections among women for whom a risk was reported.

5.1 What does your organization need to implement effective, appropriate interventions for these populations?

Group One

- Reach out to churches
- Work with social media
- If you are going to use billboards, they need to be universal across the community so it does not look like you are targeting certain communities

- Find communities that do best practices and then try to train or share with other communities; find ways to share best practices ; the state should work to create a list of best practices that other localities can use or shop from for their communities
- Network with Boys and Girls Clubs as a way to mentor youth; find ways to use these networks to support youth at risk
- Make meetings capable of accessing via conference call so individuals that are not able to travel can participate in the event

Group Two

- Money
- Need cultural sensitivity training, humility training for physicians, education and training on how to remove stigma from high-risk populations, education and training for staff about HIV and available resources, education on how to effectively educate people

Group Three

- Youth category—not getting diagnosed until becoming very ill is likely a high school problem that is being labeled as a college-age problem
- Testing should be routine part of preventative health care, which will reduce stigma around testing
- More education
- Development of a more effective way to work with injection drug user (IDU) population
- Agencies should have to focus on all populations, because all populations overlap
- Need more funding

Group Four

- Manpower to engage people—more people with passion, knowledge, and interest; some people don't think they have a stake in it
- Health awareness—under the radar somewhat
- Prevention and care need to come back together and share information
- More culturally appropriate trainings that cover subjects other than just race/ethnicity

5.2 What needs to be done at the structural level (policies, laws, and infrastructure) to reduce stigma and to ensure clients have access to services that are culturally appropriate?

Group One

- Look at our criminal transmission laws to ensure they are not a barrier to people wanting to test
- It will take a long time to make HIV a disease that is fully accepted and not closeted; we need to look at how we package education and awareness of the disease to the community; we should talk about it as just another chronic disease, not as a special disease
- Youth are seeing and perceiving having an STD as less stigmatizing; we have taught them that there is a shot or pills to take and it will be all okay; the culture has changed around STDs but has not transferred to HIV

- Pharmacies treat all disease from erectile dysfunction to diabetes; we need to work on the messaging, or we have failed with HIV; society has also shunned HIV by separating it from other STDs; we need to work on changing the discussion of HIV from isolated discussion to everyday discussion, such as we do with other diseases
- It is important to keep some of the education and outreach local so that it contains the local flavor; we need to ensure that the language becomes part of the local conversation
- We need to start education earlier and make it age appropriate; go down further than the current age range for the start of education, since by the time children become adolescents, they have already been exposed to untruths by their peers, and this is a lost opportunity
- Communities of color need to start with leaders from within their own communities first; targeting prevention and outreach is harder in these communities, so you cannot be an outsider coming into these communities
- The important part of events like today is that it is a place and opportunity for professionals to connect and build community partnerships; we need to have these meetings on a regular basis
- United Way website is 211hoi.org—this is a location to find local resources; we need to be sure that HIV resources are present among outreach and referral sites

Group Two

- The recent changes in the principal notification law help
- We should rethink HIV criminalization laws altogether
- State should stop being so careful about what needs to be said; the message needs to be bolder to reach the targeted populations (the recent Meth commercials are an example)
- Comprehensive sex education in schools
- Show the facts of HIV; it is not just a gay disease
- Create a listserv to keep stakeholders abreast of policy issues

Group Three

- Standardize HIV testing into law
- Provide more HIV education in the schools—elementary to higher education
- Increase collaboration and inter-organizational linkages among agencies
- Add multi-language and hearing impaired services
- Maintain paper copies for those who do not have Internet

Group Four

- Involve clients in legislative process and lobbying, help them tell their story
- Develop a legislative agenda
- Get HIV on the agenda of City Council meetings
- Clients need to reduce the stigma within themselves (fear of being seen at services, etc.)
- Lift the federal ban on syringe exchange

Region Five—Southern Illinois 2014 HIV Engagement Meeting
August 7, 2014

Question 1: The strategy impels us to engage entities from HIV prevention, care, and treatment; STD, TB, and viral hepatitis; mental health and substance use; housing; related supportive services; and other key stakeholders in HIV planning.

1.1 What other entities need to be engaged in this process and at what level (referral, planning) should they be engaged?

Group One

- Hospitals and hospital systems
- Referrals to Dr. Sakbani's office
- Schools (education)
- Parents (education)
- Collaborate with Cornerstone—the newsletter of Morris Library at Southern Illinois University Carbondale (SIU)—and the Adolescent Health Center
- Reach out to health care advisory boards
- Social media
- Department of Corrections—to facilitate communication after release and connections with outside health department
- Local school districts (planning)
- DCFS representation
- Juvenile justice
- Local organizations like Centerstone, a large behavioral health services provider in southern Illinois (planning)
- IDU treatment facilities like Gateway Alcohol and Drug Treatment Center (planning)
- Supply evidence-based statistics to local community such as provided at this meeting, at their meetings to give them a firsthand perspective of the impact of the disease on the community
- OB/GYN providers
- Universities and colleges
- African American Churches (peers needed)
- Parish nurses
- Jackson County Health Department has previously sent HIV service promotions (care, testing, public information) to medical providers and churches, but responses were low—0.5%
- Schools
- Carbondale High School just got permission to provide condoms with sexual health
- MSM social media involvement (Grindr, Adam4Adam, etc.)
- SIU Sports Teams
- Medical providers who could provide routine HIV testing
- Media such as radio stations, CIL, WDBX, Queer Out Loud
- Fellowship House, H-Group (now Centerstone), Women's Center program for Women in Recovery

- Women and girls conferences

1.2 What would you like to see come out of these planning efforts?

- Greater education of staff
- Greater collaboration between agencies
- More cohesive working relationship between both state and local agencies
- School districts providing twice the education
- More sex education in schools
- Social media ads
- More routine testing
- Medical provider HIV education and sexual diversity health training
- More sex education in school
- Social media ads
- More routine testing
- Social media messages on MSM apps such as Grindr on effective condom use, targeted testing promotion, linkage to care promotions, etc.

Question 2: The strategy impels us to increase coordination and collaboration across HIV prevention, care, and treatment; STD, TB, and viral hepatitis services; mental health and substance use services; housing and other supportive services.

2.1 What potential opportunities for collaboration and coordination of activities do you see?

- Opportunities to allow multiple agencies to provide input or share information about programs, resources, and costs
- Collaborate on training efforts
- Visit rural communities annually to discuss HIV & HIV services
- Doctors and primary care providers are staying, but their staff is somewhat transient
- Work with the student groups—provide train the trainer programs to develop youth leaders
- Coordination between DCFS and health workers to educate them to reduce the risk of transmitting HIV by children moving from youth into adulthood
- Routine testing within County correctional settings
- Training the providers to provide more HIV testing—making it more routine will make it more acceptable and reduce the stigma of getting tested
- Midwest AIDS Training & Education Center (MATEC) training on HIV and Hepatitis C
- Anti-bullying campaigns to decrease the abuse against LBGQTQ
- School board members need to be present at the table more often
- Harm reduction provider contacts once they leave the treatment facility
- Provider harm reduction resource cards statewide—add to HIV Care Connect website
- SIU estimates that they have about 40 people living with HIV enrolled (~10% of R5 prevalence)
- Collaborate with media outlets

2.2 What are the challenges or barriers to this collaboration and coordination?

- High transfer and turnover rates of employees
- Large rural geographic area
- Stigma
- Limited manpower
- Difficulty getting certain medical services done requiring blood draws such as Hepatitis C with co-infections
- Lack of physicians in rural geographic areas
- Lack of acceptance in the community for needle exchange and harm reduction material
- Staffing issues within the local county jails are a barrier to conducting more testing
- Rural issues—transportation challenges and no mass transit system
- Distrust
- Stigma
- Competition between churches and community groups
- Gay bar reps
- Non-gay-identifying MSM—most likely to be new positives
- SIU controls all the content going to their kids, and if it's not internally developed, it may not be used

Question 3: The strategy says three critical steps we must take to reduce HIV infection are:

(1) intensify prevention efforts in communities where HIV is most heavily concentrated; (2) expand targeted efforts to prevent infections using a combination of effective, evidence-based approaches; and (3) educate all Americans about the threat of HIV and how to prevent it.

3.1 How do we balance the demand to intensify targeted interventions for the most impacted populations and the need to provide general education and prevention services?

- Target programs around the most at risk populations
- Utilize a volunteer corps or Americorps student workers to help with general education and prevention services—trained through train the trainer programs
- Shared email list (listservs)
- Intensify education among the community (3)
- More public service announcements
- Public educators need to work more with the local public health departments to better serve the population
- No real fear of HIV anymore, youth especially need to be aware of the risk and getting into care
- Acting Against AIDS campaigns, website and Kaiser Family Foundation, we're greater than AIDS
- Promote routine testing to providers
- Use CDC slick, professionally produced videos and materials—both targeted channels with risk-targeted messages and general channels with the general population
- SIU does not want to be first to do fourth generation testing; get other medical facilities in area to adopt fourth generation testing first

- Get Quest Labs to adopt and promote fourth generation
- Get pharmacies to stock HIV Care Connect brochures with their home tests

3.2 Federal and State HIV prevention funds for Illinois were cut this year and may be cut in future years. Knowing that, what recommendations can you provide the State about ways to best intensify prevention efforts in communities where HIV is most concentrated?

- Better planning to address most at risk populations in the hardest hit areas
- At local level through collaborative efforts and information sharing
- Shared responsibilities
- Social media campaign
- Base grant scopes more on geographical area's epi data
- Transmissions rates among the demographics in the region are completely different than the rest of the state
- PREP initiative, centers of excellence
- Educating the parents more
- Engage local media
- Partner with universities
- Target migrant workers for HIV prevention services
- Make fourth generation testing more available, especially for youth with positive gonorrhea/chlamydia anal swabs
- SIU has a dirty needle turn in, but not a distribution program
- SIU pharmacy should allow students to access clean needles without a "medical reason"
- Connect new Regional Implementation Group harm reduction project (Sisters & Brothers) to sites serving IDUs and communities with IDU infections (focus on methamphetamine injection in Region)

3.3 What HIV health inequities do you see and what strategies can you suggest to address them?

- Lack of services in migrant communities
- Lack of funding to address all needed testing services
- Lack of ability to use federal funds for certain services
- Stigma—change policies and laws
- Women with HIV have female health issues that are difficult to get treated (and get payment for in some cases)—lack of providers who will accept clients and lack of funding sources for services
- Provide local physicians with consultations with specialized physicians to better serve local populations
- The high rates of new infection among IDUs
- Black MSM

Question 4: Comprehensive prevention services (including partner services) for persons living with HIV are a priority of the strategy.

4.1 What needs to be done to ensure HIV-positive individuals have access to prevention, care, treatment, and supportive services to decrease the risk of HIV transmission to their partners and retain them in care?

- Make aware of resources, provider choices, and viral load suppression
- Make aware of link in HIV treatment and viral load suppression and lowered—not eliminated—risks
- Use social media to communicate services and accurate messages to HIV
- Transportation
- Increase retention in care; identify best practices amongst various agencies
- Increase number of mental health providers in the region
- Monthly meetings with providers
- Multi-disciplinary meetings with providers
- More support groups
- Create an inter-county mass transit system
- Legislative support
- Re-engagement to care policies and incentives
- Create a paid Positive Youth Peer Navigator—no students are out about being positive
- Make sure that all providers know about and make referrals to Ryan White care services
- Engage primary medical providers to provide support and maintain connections for their newly diagnosed patients, rather than pass them off as referrals

4.2 What does your organization need to incorporate prevention for HIV positives into its array of services?

- Money
- Money for advertising
- Telemedicine linkage
- Make HIV testing a part of routine testing
- Update testing equipment for fourth generation testing
- Require third trimester testing
- Collaborate with Jackson County Health Department
- Sharing model prevention for positives policies and procedures
- Provider training

4.3 What are some challenges or barriers your organizations face in providing comprehensive prevention for positives services?

- Reporting requirements and administrative burdens
- Resource personnel
- Stigma
- Fear of being identified as HIV positive
- No people's champions—peers or providers

- Not enough support groups and difficult to engage some participants because of stigma and fear of disclosure
- Stigma regarding sexual risk
- No one wants to be out as positive
- Providers being judgmental

Question 5: To identify ways to mitigate the impact of stigma and discrimination on HIV care, treatment, and prevention. In Region Five, the latest epidemiological data suggest the following:

There was a 47% increase in the number of new cases diagnosed between 2009 and 2013 (19 new cases in 2009 and 28 in 2013). An average of 21 new HIV cases was diagnosed each year during this time period. The majority of new infections diagnosed among males and females from 2009-2013 were white. The proportion of new cases diagnosed among males and females attributed to IDU was significantly greater in Region Five compared to statewide figures (10% vs. 5%). Among males, the majority (42%) of new infections occurred among those in the 20-29 age category. Among females, the majority (35%) of new infections occurred among those in the 30-39 age category; however, a significant proportion (25%) of infections occurred among those in the 19 and under age category. More than one-third (34%) of new cases diagnosed between 2009 and 2013 were between the ages of 20-29 at the time of diagnosis; 14% of cases were 19 years old or younger.

5.1 What does your organization need to implement effective, appropriate interventions for these populations?

- Financial resources
- Accurate and available education, possibly with buy-in through the regional offices of education
- Programs with parental involvement
- Stigma against women needs to be address
- Women's group
- Kimberly Harris helping with disclosure
- Support for peer navigation
- Skype social group
- School board education (2)
- MSM social media outreach in the absence of local gay bars or LGBTQ organizations
- Implementation of IDU harm reduction services
- Routine testing and comprehensive school sex education for at risk heterosexuals

5.2 What needs to be done at the structural level (policies, laws, and infrastructure) to reduce stigma and to ensure clients have access to services that are culturally appropriate?

- Possible elimination or modification of policies relevant to youth
- Department of Corrections policies that fail to address the special needs of the correction environment
- Make HIV testing routine and don't make them sign a consent form to receive a HIV test

- Provide more support groups (2)
- Engage local churches
- Engage Southern Illinois University
- Engage local youth organizations
- Make sure front line worker have a voice when policies and laws are being written so their voices aren't ignored; they will be the ones who have to conduct these laws
- School boards are extremely conservative, more so than teachers; inform and educate them
- Strategy—poll the parents of students at a given school about at what grades they want their children to receive various aspects of comprehensive sex health education; ask the board in advance to agree to support whatever 90 percent of parents support for a given grade. (typically, 90 percent of parents will support far more topics presented at far younger ages than the school board members have supported, and so the board will discover it can support opt-out education that's far more advanced)
- Strategy—accept invitations for narrow, conservative topic presentations, but schedule the majority of time for Q&A so that learners can broaden the topic to meet their sex education needs
- Strategy—health educators can pass out question cards so that students can ask questions they might be embarrassed to ask, and instructors can build broad answers to narrow questions to ensure they cover critical material

Region Seven—Collar Counties 2014 HIV Stakeholder Engagement Meeting April 11, 2014

Question 1: The strategy impels us to engage entities from HIV prevention, care, and treatment; STD, TB, and viral hepatitis; mental health and substance use; housing; related supportive services; and other key stakeholders in HIV planning.

1.1 What other entities need to be engaged in this process and at what level (referral, planning) should they be engaged?

Group One

- DuPage County has a horrible heroin epidemic; who should be around the table for this discussion
- Corrections—we need local county jails to be champions for routine and opt out testing
- Faith based communities—there is a large disconnect in supporting the HIV/AIDS community
- Substance use and behavioral health organizations are not doing routine or HIV testing
- DuPage County is missing all HIV testing under prevention; organizations look to the Health Department to do the work and to know the gaps when funding is limited
- Hospitals—need to know about how to handle PREP and PEP, are reluctant
- The private health community pushes it off on public health clinics; they lack knowledge of billable services
- Need education for primary and secondary doctors and emergency room facilities on simultaneous HIV and STI testing

- Health insurance literacy for providers and consumers
- Need to educate on the outcome measures and standards of care for HIV as a way to show the cost benefit and public good of HIV prevention and treatment
- Schools, school boards, school nurses, teachers, and health care providers need to learn to talk about things like sexual health and number of sex partners
- Some providers aren't using all the tools in the tool box—don't know they need to have the conversation with their patients that treatment is prevention
- Private providers—never at the table, and they don't always follow the standards HRSA requires; some think they can pick and choose which standards they need to implement or monitor

Group Two

- Northern Illinois Public Health Consortium (NIPHC)
- Kane and Kendall Counties missing today
- Agencies funded to do things need to reach out to non-funded agencies
- Substance abuse, corrections, and youth agencies and organizations
- Agencies that serve LBGQTQ groups
- Consumers, especially youth and young people who are aging out
- School boards and high schools
- Immigrant and refugee serving agencies and organizations
- Local legislators
- Infectious disease and primary medical care outreach/education

Group Three

- All local health departments
- Agencies and organizations serving women, juvenile justice organizations, and domestic violence organizations
- Agencies and organizations serving drug using populations
- Consumers, young people, schools, education organizations
- Immigrant and refugee serving organizations
- Township and city managers and leaders
- Organizations serving youth in and aging out of child welfare
- Private providers, hospitals, and plasma centers
- Ryan White provider meetings with counties (provider maps)

Group Four

- Planned Parenthood—planning, referral, need contacts and networking
- High school and college mobile testing by local agencies
- Homeless shelters—planning, referral
- Aunt Martha's—advocate for more involvement (planning)
- Mental health planning community resource team
- Substance abuse programs—planning
- Hospitals—planning, referral

Group Five

- The educational system—to reach children at a younger age before they are sexually active— Illinois State Board of Education (ISBE), colleges
- Health providers, including private behavioral health providers
- Substance abuse treatment providers
- Department of Corrections, local corrections systems
- Dental providers, medical care organizations
- Minority health organizations and providers
- Non-Ryan White medical providers who will now see HIV-positive patients who have insurance
- Housing entities other than HOPWA, local housing entities
- Agencies and organizations that provide essential and supportive services, such as housing, food, etc.
- Department of Aging, senior service organizations
- Follow-up question from the group: How do we reach the people we want at the table—offer incentives such as CEUs, training

Group Six

- Over 71,000 people in Lake County are uninsured or underserved; the Health Department works with other local clinics that serve this population
- Clinics serving uninsured people and other underserved populations
- Priority in Hispanic families is instilling values in their children; there should be a bridge between communities at risk and the health care system; could the ILPHA be that bridge
- Models that work need to be shared
- Organizations that serve immigrant communities
- Religious and faith-based organizations, churches
- Organizations serving communities of color
- Any organization serving at-risk populations
- Local legislators
- Community leaders—the people who others in the community listen to
- Adult literacy organizations and local libraries
- Funders

1.2 What would you like to see come out of these planning efforts?

Group One

- Education and accountability
- More outreach to providers, especially private providers; let them know the services that are out there and the standards; how do you assure accountability to the guidelines
- What are the barriers to providers for providing testing; why are they not testing
- Surveillance data is good, but providers do not think incidence is in their community and don't see screening as needed; need provider education on the importance of screenings; providers may fear that they don't know what to do if they get someone who is positive

- People are uncomfortable with talking about sex; there is a need to help with the conversation; there is a cultural aspect of talking about sex to patients and the need for services when they are tested and find out they are positive
- There is still a big issue with stigma in the community. Affordable care is more open in Illinois, and people may have more options, but there is a need to sensitize new providers
- Need to talk about linkages to care and treatment as they relate to individuals who are diagnosed—need to help them learn how to navigate the health system
- Would like to see providers chosen through ACA become more culturally competent to care for new populations

Group Two

- Movement to meeting ILHAS goals
- Making connections and linkages to above agencies
- Stronger consumer support and involvement
 - Joliet Junior College Will Fund Hope Anti-Stigma Initiative
 - Lake County Stands Against Stigma
- Collaboration and eliminating silos
- Too many reporting systems
- Putting the patient first in care and prevention (communication)
- IDPH/MATEC maps by Ryan White providers linkage to care and what they offer

Group Three

- Movement toward meeting goals of ILHAS
- Action upon the ideas generated
- Local community coalitions—“stop the stigma”
- Stronger consumer advocacy boards, identify needs and gaps
- More social media networking and replication (Lake and Will Counties)
- Collaboration among organizations, better communication, shared data, more connection between care and prevention

Group Four

- Homeless shelters representation
- Referral—need contacts and networking
- Mobile testing by local agencies increased
- Enhanced, established communications
- Mental health departments, substance abuse and hospital representatives

Group Five

- Training for those who do not work in the field of HIV
- More people at the table, a more diverse group of people at the table
- An organization that sets the agenda for HIV across the state, by people infected and affected by HIV
- Addressing standards of care for HIV
- Report on outcomes, clear outcomes on an ongoing basis

- Stronger advocacy in the regions
- Independent advisory groups
- Training for clients to be self-advocates
- Follow up question from the group—who should be the conduit to make these things happen

Group Six

- More people who know their status—everyone should know their status
- Teachers have a lot of contact with their students, a lot of exposure; kids need health education, and schools—collaborating with health departments and NGOs—can really have an impact; it's a way to reach families as well
- The schools should be working outward into the community, and the community should be working inward to the schools
- Sometimes parents don't want the schools involved in health education with their children (parents can opt out of any part of the curriculum on behalf of their children)
- Exemplary Sexual Health Education (ESHE)
- More agencies that know what other agencies are doing
- Perhaps smaller and newer providers could get a share of the resources so that they can provide needed services including mental health and substance abuse
- Chicago Department of Public Health (CDPH) could structure its Requests for Applications (RFAs) so that care funding would have a set aside for specific geographic areas in proportion to the prevalence in that geographic region; this would ensure that each segment of the EMA gets its epi-based share of each care service resource
- Currently, many parts of the suburban EMA are just doing without one or more critical Ryan White service
- Capacity to deliver specific top-notch services to people living with HIV has never been built in many parts of the EMA because providers near specific epi hotspots have never been funded, and thus could not develop their expertise; they were never funded because the lack of geographic funding segmentation in the EMA's RFA forced smaller suburban agencies to compete against "the big dogs," the major urban institutions near the early urban epicenter with decades of experience
- The result is that these services 30 years later remain challenging to access for suburban people who are living with HIV who lack a vehicle
- Reportedly, CDPH reported at a recent CAHISC meeting that EMA Ryan White funding outside of Chicago was only 11 percent of total Ryan White service dollars to serve about 20 percent of the EMA's PWHIV
- One option for building suburban care capacity is sole sourcing to some of the big dogs who have the expertise to provide assistance to newer or smaller organizations in underserved geographic areas
- Voices in the collar counties should be better heard when it comes to slicing up the pie
- At least 20 percent of Chicago Area HIV Integrated Services Council (CAHISC) meetings should occur in the suburban areas, so CAHISC members can experience taking public transportation to remote suburban portions of the EMA in order to feel the burden that underfunding suburban services relative to suburban prevalence proportions places on suburban PWHIV who want to access their share of the services, which have been concentrated in urban centers far from their communities

Question 2: The strategy impels us to increase coordination and collaboration across HIV prevention, care, and treatment; STD, TB, and viral hepatitis services; mental health and substance use services; housing and other supportive services.

2.1 What potential opportunities for collaboration and coordination of activities do you see?

Group One

- Now that we have this new insured population, how are they coordinated within their health care plan; we need to look towards how to educate the programs to coordinate (Marketplace, Medicaid, and Medicare); need to work with new insurance marketplace plans and other third party providers
- Medical schools—we can work with them to develop new curricula on the importance of serving all patients
- Correction and county jails
- Faith communities
- Substance use and mental health providers
- Colleges and universities.
- Team up with state legislators; they can get right into the minister's office in faith communities about care and compassionate outreach to special populations such as HIV
- Aldermen and local public bodies; politics and religion are tightly connected, believe it or not
- Local community centers, senior centers
- Need more positive individuals who are willing to put a face to the disease
- Reach out to community services or volunteer organizations as a champion—need them on the HIV Planning Group

Group Two

- IDPH HIV and STI collaborating more
- Perinatal HIV and syphilis
- Guidance for IDPH to local agencies to collaborate more—STI/HIV/Ryan White; now have data and security measure
- Disease Intervention Services (DIS) designees

Group Three

- More frequent data matched—STD, HIV, prenatal HIV with congenital syphilis
- Collaborate with Chicago Department of Public Health (CDPH) and Cook County Department of Public Health (CCDPH) on this issue
- More integrated programs at local level
- Guidance from IDPH about integration, program collaboration, systems integration (PCSI)—start with HIV data and the HIV section

Group Four

- Representation by each at meetings—mental health, substance abuse services, housing, supportive services to improve communication, networking, referrals

Group Five

- Training of peer navigators, empowering clients
- Follow up question from the group: Who do you collaborate with to achieve the goals? Should there be a percentage of clients required at the table at all times?

Group Six

- Opportunities to learn from each other about best practices, about what works and what does not
- Make sure that there is better coordination between surveillance and care (between the people funded)
- An association in each underserved county with conferences and other resources with information specific to their needs and interests
- Providers can maximize the impact of funding through collaboration
- Survey private providers to find out what their interests and needs are and what they want to and would be willing to do (it's hard to get to the private providers)
- Engage hospitals and health care providers

2.2 What are the challenges or barriers to this collaboration and coordination?

Group One

- Faith-based community and cultural communities that struggle with stigma issues; knowing that, we may need to reach them through other champions such as politicians or local community leaders
- Training and supports are limited in how to outreach and interact with agencies outside our normal network; how do we train our current providers to reach out and interact with faith-based communities and other “not normal” partners
- Language
- HIV is now one of many healthcare concerns; how do we coach, interact with, or collaborate with other healthcare agencies specific to other conditions
- Addiction is a medical condition; how do we work with law enforcement to sensitize them to the needs of our clients, especially IDUs
- There is fear and stigma in the community with some high-risk populations such as IDUs; how do we reach out to and work with these populations to ensure they receive prevention services (we do not need to criminalize or prosecute them to help them)
- Funding—resources to promote innovation is an issue, especially for HIV prevention systems in Illinois—how can we do innovative special program funding
- Need champions—youth or adults to reach out to the HIV community; how do we bring messages back to difficult communities that are on the fringe
- Need to know how to work with young MSM of color; clinics could provide outreach to local bars and partner with older MSMs to hang outside the bar and provide prevention education; use social media

Group Two

- Bureaucracy
- Different reporting systems

- Knowing the information other service agencies need, and sometimes information we need
- Ego
- Fee for service per agency competing
- Administrators' support

Group Three

- Bureaucracy
- Lack of communication
- Lack of information
- Fighting over grant scopes
- Lack of support at the top
- Low prevalence counties

Group Four

- Confidentiality
- Money
- Manpower
- Competition

Group Five

- Agencies do not play well together; competition for funding doesn't create a willingness to work together
- Smaller organizations are eaten by larger agencies, don't always have the opportunity to grow because funding is lower; smaller agencies depend on timely funding to sustain them and cannot float a budget until payment is received
- Capacity building and technical assistance may not be available to smaller organizations, or they may not be aware that it is available

Group Six

- Funding (4)
- People who don't volunteer in their own communities—they travel all over to do that, but we have needs here
- Staff are stretched thin, need more staff (3)
- Lack of interest in rural communities
- CDPH hasn't made the investment in HIV care with Ryan White dollars in the suburbs proportionate to the people who need it, so the infrastructure isn't there (2)
- The funding structure needs to be changed to fix that (2)
- 50 percent of Illinois HIV incidence is outside Chicago, but only 33 percent of the federal prevention resources are available for outside Chicago (the CDC prevention formula is based solely on prevalence, which makes sense for care, but not prevention, since incidence comprises the set of events that prevention needs to stop; the need for prevention correlates more closely to incidence than prevalence)
- People who don't know their status
- People don't get tested because they don't know they are at risk

Question 3: The strategy says three critical steps we must take to reduce HIV infection are:

(1) intensify prevention efforts in communities where HIV is most heavily concentrated; (2) expand targeted efforts to prevent infections using a combination of effective, evidence-based approaches; and (3) educate all Americans about the threat of HIV and how to prevent it.

3.1 How do we balance the demand to intensify targeted interventions for the most impacted populations and the need to provide general education and prevention services?

Group One

- Balm in Gilead is an organization we can reach out to find out how to best reach young black MSM who have risky behaviors; need to have someone who looks like them to deliver the messages
- Look at larger networks to partner with to leverage resources to reach vulnerable populations
- Agencies are not being funded to do education, which is still very important
- Identify one group in our community and start from there
- Start working on building a social network of those coming in for testing
- Someone needs to take on education even if not funded within the program
- Suggested reaching out to political partners; difficult to get on the agenda or get in front of schools boards to tell the basic story of the HIV continuum of care (aka the Gardner Cascade)
- How to get information to the county boards of health who should be these meetings
- Maintain good relations with hospitals to do more routine testing
- Need to reach out to let them know who and how to link clients to the system of care
- May get new positives, so need to get information out to private and public providers to let them know about services
- General education needs to be at higher levels—grand rounds at hospitals, educating our own leadership
- Need to do health network memos—easy ways to remind providers about the components of good HIV health care
- Need to educate that immediate treatment is key (not just at CD4 levels at 200 or lower)
- Treatment does more for HIV prevention than using condoms
- When you combine them, there are even higher positive health outcomes
- Message that those who are HIV positive are still active, living persons who have loving relations and children—need to educate providers about this fact—abstinence is not the only message to send, and it is ineffective

Group Two

- Multiple funding streams
- Under-utilized interventions for positives such as Linkages to Care (LTC), Safer Sex Skills Building (SSSB)
- More collaborative between agencies, even with the same funding

Group Three

- Need to normalize the marketing around HIV; ads are too targeted
- Stigma and disclosure issues
- Diversify funding streams

- Multiple methods for working with people living with HIV/AIDS

Group Four

- Extend our reach and communication through establishing contacts and two-way referrals with more agencies

Group Five

- Social marketing, targeted social marketing concept like Pepsi, McDonalds, Coca Cola, etc.—tailor messaging for each group
- Ensure access to factual information
- Collaborating with others, such as Boys and Girls Club, YMCA/YWCA, to reach youth; collaborate with agencies that serve the targeted groups
- Don't forget the seniors who have aged with HIV infection for many years; target unique messages to that group also

Group Six

- Select research-vetted, behaviorally effective curricula and engage the school systems
- Teachers have sometimes dismissed these curricula as “canned,” opting instead to develop their own knowledge-based curricula that research indicates have little impact on behavior
- ACA provides potential for more widely disseminated health care, so there is potential there for greatly expanded general population HIV testing
- We need to emphasize prevention equally with care—don't want to take dollars away from care, but want prevention dollars to be equal with care
- The growth of routine testing nationwide has shifted resources and focus away from targeted testing and towards general population testing
- The group seropositivity rate for routine testing is 10-20 percent that of risk-targeted testing, but it is cheaper per screen because it does not involve risk counseling, except for those who test positive
- Routine testing can also be a way to reach people with HIV education
- Care providers provide HIV prevention by lowering the viral loads of PWHIV, conducting partner services, etc.

3.2 Federal and State HIV prevention funds for Illinois were cut this year and may be cut in future years. Knowing that, what recommendations can you provide the State about ways to best intensify prevention efforts in communities where HIV is most concentrated?

Group One

- Need to have education and leaders at the table
- Need more data on viral load mapping; this will help with targeting outreach and education—may help locals to target communities and provide prevention outreach
- Use data to drive the work with prevention and testing outreach
- Where are the individuals who are positive and not in treatment
- Can we target physicians who test and find positives to see if they have reached out to find out if treatment is occurring
- Use the surveillance data to see how we can better work with and educate providers

- Incentivize health care
- Disease Intervention Specialist (DIS) systems statewide are a help with prevention; issues on how we bill and get paid for efforts to get clients linked into care and partner services
- There is a stigma in how we provide partner services
- DIS work is hard; it is hard to connect with partners, and there is anger
- There is a barrier in how we outreach to partners
- We need better training on DIS outreach
- The laws around HIV add to the barrier and stigma of the disease and the DIS process
- Agencies are having difficulty in meeting their grant scopes since no one wants to identify as part of a risk group
- There are still agencies that want to test (county jails); partnership options are needed—this may be an option for county jail law

Group Two

- Prevention for positives
- Upgrade reporting systems
- Ongoing ACA education

Group Three

- Maintain African American Response to AIDS Act funds
- Level funding is not level funding
- State education to providers on HIV and the ACA

Group Four

- Appropriation of funds from lesser impacted areas to more concentrated areas while accessing larger groups with a broader circle of influence

Group Five

- Address behavioral health issues; taking the pill is a behavioral issue; we must get to why this younger generation is not tuning in to the prevention messaging
- Conduct appropriate outcome evaluation of the DEBI
- Sustain what works, cultivate those with passion
- Expand what is considered prevention, such as maintaining basic life needs (hierarchy of needs)

Group Six

- More pro bono support
- A health fair for communities at risk
- Funding for the initiation of health fairs; it costs time and money to set them up—funding would stimulate that
- How can we get sponsors for health fairs (private funders in the community)

3.3 What HIV health inequities do you see and what strategies can you suggest to address them?

Group One

- There are inequities among young minority MSM
- Social network testing, social media, and working through faith communities are needed
- This is difficult because often they do not want to out themselves
- So much bad information, misinformation, and lack of information on the ACA and other insurance venues and what is available to individuals
- Positive messaging is critical
- Educate the community that HIV is a covered disease
- Need to be cautious about too much targeting, as you then neglect another group whose incidents begin to rise; it is a balance how to target and yet not lose progress made with other groups
- Poverty is a major barrier; census, income, and STI maps would help with targeting prevention and care rates
- What can we learn from other successful health campaigns to see how we can market or work on sustainable activities
- Youth have not been taught harm reduction, only condoms and abstinence; sex education is an addition to fill the hole and is not addressed in a comprehensive manner; we need to teach that everyone is open to exposure

Group Two

- Need for more bilingual programs and staff
- Reduce stigma and normalize HIV
- Disclose education help
- Lack of youth education
- Staff education
- Effect change at all levels—education, incarceration, immigration, housing, employment, health (schools, DHS, DOC, FQHC, HUD)

Group Three

- Need more education and outreach to reduce disparities
- Overlapping community issues—unemployment, lack of education, poverty
- Local level engagement

Group Four

- ACA eliminates many of the barriers, though there are still disparities in minority and poverty stricken areas
- Increase ACA promotion

Group Five (no responses)

Group Six

- Inequities by population—younger black and Latino MSM, women of color
- Strategies:
- Education, awareness
 - Sharing the resources

- Social networking, apps
- Syringe availability
- Comprehensive sexuality education in the schools

Question 4: Comprehensive prevention services (including partner services) for persons living with HIV are a priority of the strategy.

4.1 What needs to be done to ensure HIV-positive individuals have access to prevention, care, treatment, and supportive services to decrease the risk of HIV transmission to their partners and retain them in care?

Group One

- Make sure all providers know that treatment is key and that they need to combine treatment with condoms; all STI and HIV clinicians need to be educated in how to have the conversations with clients
- Work with partnerships with in person counselors to assist with linking to insurance and then to care
- Health Insurance literacy—need to be well versed with insurance and billing information; teach providers and clients how to navigate insurance, which is key to keeping individuals in care
- Teaching clients appointment etiquette—new ways of being responsible for this health care paradigm shift
- What do we need to do to help facilitate education on what it means to have a responsible and accountable patient-provider relationship—need champions in each of the medical systems, then they need to see that they are doing well

Group Two

- Reduce stigma, educate primary medical providers
- Seamless transitions from testing to care
- Housing
- Transportation
- Mental health services
- Wrap around services essentials

Group Three

- More seamless coordination
- Wrap-around agency successes and being knowledgeable about successes
- Reduce stigma
- Need for stable housing and transportation

Group Four

- Improved access to electronic medical records—reevaluate policy and conflicts of policy among programs

Group Five

- Marketing campaign
- Get personal messaging out—the new personal stories with new faces—“I am the face of HIV”
- More Gilead type commercials, anti-stigma push
- Back to basics messaging about prevention and treatment
- Community outcry and advocacy

Group Six

- Identification
- Make sure that Ryan White dollars are proportionate to prevalence share in Chicago vs suburban Cook County and the Collar Counties
- Promote the ACA
- ACA cost including deductibles—the Lake County Public Health Department is starting to see people who have had ACA insurance for a couple of months and now can't afford the premiums or deductibles
- Less stringent rules for people to access services
- Re-engagement in care

4.2 What does your organization need to incorporate prevention for HIV positives into its array of services?

Group One

- Need to work with education on the insurance area—need to know focus on outcomes of health care
- Some private pay providers went into private work to avoid challenging clients, now these clients have insurance and may be in their offices—need to change the culture of new patient/provider relationships
- Work directly with clinics providing services and with case managers and agencies, then need to find positives
- Need to get into the positive network—need competencies to reach out to new positives and get them into services; we need training on how to reach this vulnerable population, to link them to services at the time of diagnosis, and to educate the other systems they will be linking to

Group Two

- Administration support
- Increase use of peer programming
- Finding key stakeholders to bring in those at risk
- Building relationships with HIV care providers to supplement their services

Group Three

- Collaboration between prevention and Ryan White
- Elevate the role of prevention
- Educate operations level staff

Group Four

- Increased referral options among providers
- Increased access to training for local community partners and agencies

Group Five

- Cultural humility, have to know how to put the word out
- Prevention and care organizations working together

Group Six

- Lake County Public Health Department does this
- Health Department politics in some counties are a barrier to service provision
- Health Department extension into schools is good (school based clinics, for example)
- Medical homes
- Education accessible in the schools, at home, in the community

4.3 What are some challenges or barriers your organizations face in providing comprehensive prevention for positives services?

Group One

- Conflicting priorities
- Staffing issues
- There are only so many hours in the work week
- Restrictive laws that limit how you can outreach and track
- Need to develop a PACPI for adults; the AMA is in Chicago—are we reaching out to them to have them at our meetings
- No linkage to private providers
- Is there a national private network to tap into for creating linkages

Group Two

- Being able to bill for services—Medicaid, HMO/PPO, Medicare
- Knowing where to refer—infectious disease, Ryan White
- Acknowledging there are positives in your community
- Getting clients to buy in and come in to services
- Look at geography of where clients lives
- Make connections with case managers or agencies

Group Three

- Getting clients motivated
- Coordinating with Ryan White
- Not having the caseload
- Incentives

Group Four

- Identifying appropriate referrals for overlapping risks
- Overall, challenges involve staffing and funding

- Decrease rivalry among agencies

Group Five (no responses)

Group Six

- Not all people who are positive accept services
- Training for staff on what to do in these circumstances is helpful (partner services training)

Question 5: To identify ways to mitigate the impact of stigma and discrimination on HIV care, treatment, and prevention. In Region Seven, the latest epidemiological data suggest the following:

The proportion of new cases that are female declined steadily between 2008 and 2011. In 2008, 24.8% (N=39) of all new cases were female, and, in 2011, 19.9% (N=31) of all new cases were diagnosed among females. The proportion of new cases diagnosed among females increased between 2011 and 2012; 24.7% (N=44) of all new cases diagnosed in 2012 were female. Between 2011 and 2012, there was a 42% increase in the number of new cases diagnosed among females: there were 31 new cases among females in 2011 and 44 in 2012. Overall, females accounted for 22.9% (N=199) of all new diagnoses between 2008 and 2012.

The number of new cases diagnosed among whites decreased 9.4% (N=5) between 2008 and 2012, while the number of cases diagnosed among Hispanics and blacks increased by 40.5% (N=15) and 6.3% (N=3), respectively. The proportion of new cases diagnosed among Hispanics increased from 24.7% in 2008 to 32.7% in 2012. Overall, between 2008 and 2012, blacks accounted for 33.1% (N=270) of all new cases, followed by whites (32.4%, N=264), and Hispanics (28.3%, N=231).

The proportion of new cases diagnosed among persons in the 20-29 age category increased from 27.4% (N=43) in 2008 to 31.4% (N=56) in 2012. Overall, 32% (N=278) of people diagnosed between 2008 and 2012 were in the 20-29 age category. The number of new infections diagnosed among persons in the 20-29 age category increased 30% between 2008 and 2012 (from 43 cases in 2008 to 56 cases in 2012).

Men who have sex with men (MSM)—particularly white MSM—represent a significant proportion of HIV new infections. MSM accounted for 64.4% of new infections between 2008 and 2012 (N=371) and 61.5% of new infections in 2012 (N=64) (among all cases with a reported risk). White MSM accounted for 36.7% (N=136) of all infections among MSM between 2008 and 2012, followed by Hispanics (29.6%, N=110) and blacks (28.6%, N=106). Between 2008 and 2012, heterosexual contact accounted for 87.8% (N=86) of all new infections among women for whom a risk was reported.

5.1 What does your organization need to implement effective, appropriate interventions for these populations?

Group One

- Need more support tapping into social media; the restrictions at some agencies are hard—
need ongoing support for developing social media outreach

- Prevention education needs to be put out on social media, especially for youth
- Need funding that outreaches to social media sites; need the locals to open or expand limitations to social media access; social media could be a great tool to help de-stigmatize the disease
- Financial and technical support for social media outreach, this new intervention; how does the IDPH help with providing education to local HDs and funded agencies to see the evidence base, outcomes, and impact of the work
- Need to collaborate with faith-based representatives and politicians to open doors for HIV community education
- Need to do more education at younger ages; need to reach out to the educational systems

Group Two

- More funding opportunities, especially for youth education
- Don't be afraid to be visible, continue educating
- Use peers more

Group Three

- More money
- Education to reduce stigma
- Education funding streams
- Use of peers

Group Four

- Public education, in general
- Identify commonalities in the data and plan increased, more specific outreach

Group Five

- Personal stories from all (children, women, men).
- Coalitions against stigma, bringing in lawmakers, faith-based and grass roots organizations.
- Bring in the educational component-reaching the youth
- Be consistent and constant with messaging

Group Six

- Funding—keep it available, concern about a trend of thinking that everyone is insured and will be taken care of
- Is the stigma in the collar counties around HIV or around MSM (seems to be a shift away from MSM stigma in Lake County)
- Also stigma lessening around HIV—it's now a chronic disease, education and information is reducing stigma as is media support; HIV care no longer segregated in clinics and hospitals; kids growing up knowing about HIV
- Discrimination does still exist, people with HIV may be avoided; eliminate this through more education, better access to services for the person, the family, and partners
- More talking de-stigmatizes HIV
- Mitigate the impact of stigma by making HIV more accepted
- We need more champions talking about and de-stigmatizing HIV

- Internalized fear still exists all over
- People still seek services outside their community to avoid others knowing their business
- Suburban MSM still report stigmatizing responses from their medical providers, which makes them anxious about and reluctant to access health care services

5.2 What needs to be done at the structural level (policies, laws, and infrastructure) to reduce stigma and to ensure clients have access to services that are culturally appropriate?

Group One

- HIV Confidentiality Act needs to be revised to open the way we can talk to our clients; need to help with limiting stigma; need to be able to tell if they are HIV positive when they call; need to be able to give better information to the client up front so they are more willing to work with us; cold calls are hard; current laws on DIS are so uncomfortable when we reach out
- IDOC is working on and believes that education and communication are critical for HIV prevention
- Look to community-based organizations to reach out to the legislative body
- Health departments employees are restricted from advocating to legislators and promoting laws that are helpful; more systems approach to reaching out to the community and support legislation that is positive for the HIV movement
- Need decision makers here at the table as part of the conversation; we are missing those with the authority to make decisions
- Medical providers only act when their license or lawsuits are in the picture—how do we change this dynamic
- There needs to be teeth behind the issue of people who have been in health systems and never been offered testing until they are “late testers”
- IDPH needs to do something in terms of public service announcements and provider education to inform doctors and medical providers about treatment and prevention guidelines, PrEP, and what is happening in the field that is new

Group Two

- Normalize and de-stigmatize HIV testing by agencies and primary care providers
- More local coalitions
- More local government (representatives, senators) involvement, plus ensure that they are correctly educated
- More balanced approach to focused testing vs. turning people away
- More client involvement to advocate for themselves including lobby days: signing up/volunteering, knowing what politicians are voting for, knowing who your representatives are, knowing what services you are receiving
- Need better policy to get more culturally and linguistically competent doctors/providers

Group Three

- More coalitions
- More law involvement
- Balance the need for focusing on high-risk with turning people away

- Have real people share stories with lawmakers
- More culturally competent medical providers

Group Four

- Again, increased public education and improved utilization of social media and websites

Group Five

- Stop minimizing the public health role in HIV prevention—this chips away at public health
- Decriminalize non-violent drug offenses
- Always a need for education
- Sensitivity training for law enforcement
- Address system-wide opposition
- Peer programs

Group Six

- Education—inclusion of LGBTQ risk reduction issues in school sexuality curricula
- SSE (Safe Supportive Environment) as a best practice (15 targeted districts right now through CDC grant—can ask Reginald Patterson for more info—the grant also include SHS and ESHE)—this is a long-term investment
- Physicians and other health care providers can discriminate against IDU and MSM)—solution is medical school and continuing medical education (CME) cultural competence training; cultural competence is also a training need for other health care providers
- Connections for Abused Women and their Children (CAWC) implemented a program at Stroger where physicians would go through a series of questions when there was any sign of domestic violence, leading to support—this could be a model for HIV to educate people right when they come in, do the education and find out who else might be infected (family member, partner, etc.) to extend services
- What can be done with EMRs to make testing be more routine and therefore less stigmatized
- Make routine testing a standard through medical training, hospital accreditation, etc.
- IDPH could take a role by reaching out to medical schools and asking what they're doing to prepare physicians in the area of cultural competence, communicating HIV diagnosis, etc.
- Find a way to reach isolated communities with services (and information for providers)