Cuyahoga County Regional Ryan White Planning Council

New Member Orientation Refresher/Training

October 12, 2016

12:00 Noon – 4:00 p.m.

Welcome and Introductions

Please Share:

- Your Name
- Affiliation?
- Length of time associated with Planning Council
- Most important expectation for today

Review of Agenda: Topics

I. Why do Planning Councils (PC) exist?
II. Where does Ryan White funding fit into the overall system of care?
III. What does this Planning Council look like, what is it supposed to do and not do?
IV. How does the Planning Council work?
V. Who does this Planning Council serve, where do they live, and what do we know about them?

Suggested Ground Rules

1. Focus on our shared purpose, *"the best possible care for people living with HIV in the Cleveland TGA."*
2. Ask questions – it helps everyone learn
3. Wait until recognized to speak
4. Treat everyone with respect
5. Try to identify both problems/challenges and practical solutions.
6. Recognize that the discussions may have to be limited to move the agenda.
7. Identify topics for future training opportunities.
8. Other ideas/suggestions?

Section I

Why do Planning Councils exist?

"Ryan White Legislation"

Ryan White Legislation

Who Was Ryan White?

- A young male, one of the first children, one of the first hemophiliacs. He was diagnosed with AIDS at 13, following a blood transfusion in December 1984.
- He died in April 1990, a month before his high school graduation.

Ryan White HIV/AIDS Treatment Extension ACT

- First enacted into law, August 18,1990 as the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act.
- Amended & reauthorized 4-times: 1996, 2000, 2006, and 2009.
- Largest Federal government program specifically designed to provide services for People living with HIV disease (PLWH)
- August 18, 2016 marked the 25th Anniversary of the Care Act.

Purpose of the Legislation

- To "Address the unmet care and treatment needs of persons living with HIV/AIDS who are uninsured or underinsured, by funding primary health care and essential support services that enhance access to and retention in care"
- No longer "emergency relief for overburdened health care systems
- Now a "program for providing life-saving care for those with HIV/AIDS"

Ryan White – 25 Years Later

- Funded at $2.32 billion in FY2015
- More than 1.2 million people in the U.S. are living with HIV.
- Serves more than 500,000 who do not have sufficient health care coverage or financial resources to manage the disease.
- 81% of program clients retained in care.
- More than 78% are retained in care being virally suppressed.
- No longer considered a deadly disease, now a manageable chronic condition because of access to high quality health care and appropriate treatment.

Ryan White Parts

Part A: Funding for 52 eligible metropolitan areas (EMAs) and transitional Grant areas (TGAs) that are severely & disproportionately affected by the HIV epidemic.

- **EMAs:** an area must have reported at least 2,000 or more AIDS cases in the most recent 5 years and have a population of at least 50,000.
- **TGAs:** an area must have reported 1,000-1,999 AIDS cases in the most recent five years and have a population of at least 50,000.

Ryan White Part A, *cont'd*

Part A funds may be used to provide a continuum of care (i.e., medical and support services) for people living with HIV disease. Support services ***must*** be linked to medical outcomes.

- 2014 Ohio *Part A* Grant Awards

Grantee	Final Formula Award	Final Supplemental Award	Final MAI Award	Total Part A Award
Cleveland, OH	$2,836,803	$1,348,819	$348,941	$4,534,563
Columbus, OH	$2,866,700	$1,250,767	$250,945	$4,368,412

Ryan White Part B

- **Part B:** Provides grants to States, U.S. Territories and the District of Columbia.
  - Part B grants including a base grant, the AIDS Drug Assistance Program (ADAP) award, ADAP Supplemental grants, grants to States for Emerging Communities and an award for Minority AIDS Initiatives activities.
  - Grants are State department of health or other State entities responsible for implementing and managing state public health programs.

Ryan White Part C

Part C: Provides Early Intervention Services funding and Capacity Development Grants.

- 2014 Ohio *Part C* Early Intervention Grant Awards

Organization	Location	Award
Ursuline Center, Inc.	Canfield, OH	$316,469
Cincinnati Health Network, Inc.	Cincinnati, OH	$839,753
Care Alliance	Cleveland, OH	$231,563
University Hospitals of Cleveland	Cleveland, OH	$504,830
AIDS Resource Center Ohio, Inc.	Columbus, OH	$542,005
Research Institute at Nationwide Children's Hospital	Columbus, OH	$475,000
Portsmouth, City of	Portsmouth, OH	$249,219
University of Toledo	Toledo, OH	$460,326

Ryan White Part C, *cont'd*

- **Part C:** Provides Early Intervention Services funding and Capacity Development Grants.
  - 2014 Ohio *Part C* Capacity Development Grant Awards

Organization	Location	Award
Care Alliance	Cleveland, OH	$100,000
Research Institute at Nationwide Children's Hospital	Columbus, OH	$100,000
Saint Josephs Mercy Care Services	Dayton, OH	$100,000

Ryan White Parts *cont'd*

Part D: Services for Women, Infants, Children, Youth and their Families. Part D funds: (1) family-centered primary & specialty medical care; and (2) support services.

- 2014 Ohio Part D Grant Recipients

Organization	Location	Award Amount
University Hospitals of Cleveland	Cleveland, OH	$399,652
University of Toledo	Toledo, OH	$523,950

Ryan White Parts *cont'd*

Part F:

- Special Projects of National Significance (SPNS)
- HIV/AIDS Education & Training Centers (AETCs)
- Dental Reimbursements & Community Based Dental Partnerships
- Minority AIDS Initiative

Consumer Decision Making

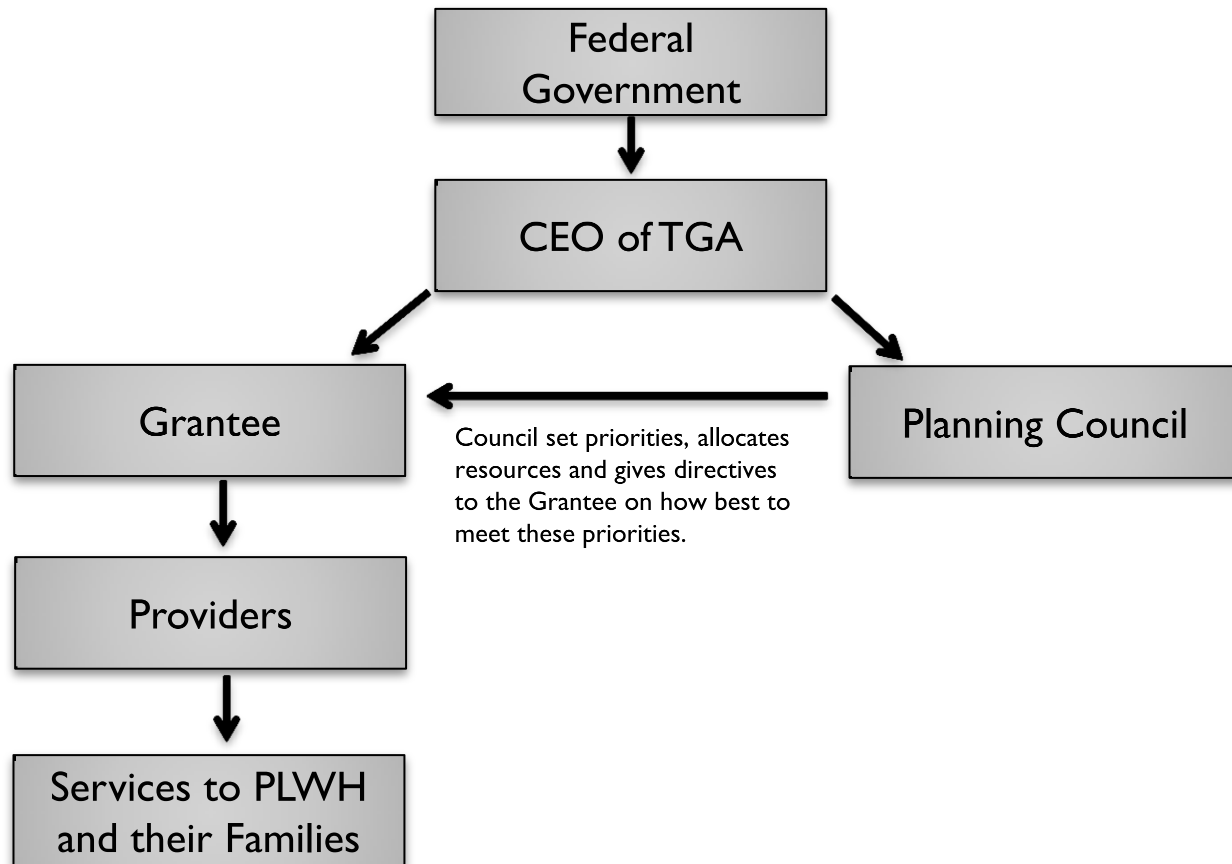
- Consumer involvement & decision-making = core component of Part A
- **Legislative requirements**
  - Planning Council (PC) composition *(33% unaffiliated consumers)*
  - PLWH input to needs assessment & comprehensive planning.
- **HRSA Expectations**
  - Strong, independent, trained & respected consumer voice on PC & committees.
  - Focus on use of consumer data for decision-making (not "impassioned pleas").
  - Respectful interactions that follow legislative intent and Codes of Conduct.

Planning Council Relationships and Responsibilities

Part A Involves Many Relationships

- **Within the PC:**
  - Membership
  - PC Support staff
  - PC consultants
- **Between, PC and:**
  - Grantee
  - County Executive
  - PLWH Community
  - Other Planning Bodies
  - Provider community
  - HRSA/HAB
- **Between Grantee and:**
  - Planning Council
  - PC support staff
  - PC consultants
  - ODH
  - County Executive
  - PLWH Community
  - Providers
  - HRSA/HAB

Summary: Flow of Part A Decision-making and Funds



Shared, Cooperative Roles between PC and Grantee

- PC and Grantee are independent bodies that need to work well together to fulfill Ryan White purposes.
- Many shared legislative roles & responsibilities
- Interdependence and linked tasks
- Pressure points, tensions need to be identified and addressed
- One tool for managing the relationship is a Memorandum of Understanding (MOU).

Benefits of an MOU between the PC and Grantee

- Clarifies roles & expectations of Grantee and Planning Council.
- Describes expected communications and interaction
- Specifies information sharing/reporting
- Provides times frames and deadlines
- Grantee and PC co-chairs worked together and completed an MOU for the Cleveland TGA last month.

Grantee and Planning Council Roles and Responsibilities

Role	Grantee	PC
Planning Council Formation/Membership/Operations	* (CEO only)	*
Needs Assessment	*	*
Comprehensive Planning	*	*
Priority Setting & Resource Allocations (plus reallocations)		*
Directives (how to meet each priority)		*
Coordination of Services	*	*
System of Care	*	*
Procurement/Contracting	*	
Contract Monitoring	*	
Clinical Quality Management	*	(SOC input)
Performance/Cost-Effectiveness & Outcomes Evaluation	*	* (option)
Assessment of the Administrative Mechanism		*

Section II

Where does Ryan White funding fit into the overall system of care?

Scope of the National Epidemic

- **Number of people living with HIV disease:** 1.2 million
- **Number of AIDS deaths since beginning of epidemic:** 698,219, including more than 13,000 in 2013.
- **Number of new infections diagnosed in 2014:** 44,784
- **Percent of HIV+ people who are unaware of their status:** 13%
- **Percent of people with HIV who are virally suppressed:** 30%

Ryan White as *"Payer of Last Resort"*

- Legislation requires that Ryan White grant funds not be used to pay for items of services that are eligible for coverage "under any State compensation program, under an insurance policy, or under any Federal or State health benefits program" [Section 2605(a)(6)]
- HRSA policy states that Ryan White "may pay for services that fill the gaps in coverage of these other private or public health care programs but the funds cannot be used for services that should be reimbursed or paid by the other payers"

Implementing Payer of Last Resort Requirements

Providers expected to:

- Determine client eligibility for other programs like Medicaid and Medicare.
- Help clients apply for such programs
- If they offer Medicaid-eligible services, become Medicaid-certified
- Bill other payers for costs wherever feasible
- Use funds obtained from other sources as "program income" to "further eligible project or program objectives or cover program costs"

Questions

Not that we've discussed the history and the difference sources of Ryan White funding.

1. What can we do to improve our efforts to identify those with HIV healthcare needs?
2. How can we improve coordination of services to leverage the limited resources?
3. Other Questions/comments?

Break

“Let’s take a 10 minute Break”

Section III

What does a Planning Council look like, what is it supposed to do and ***NOT*** do?

Planning Council Representation and Reflectiveness

- **Representation:**
  - ✓ Membership must include specific legislative categories
  - ✓ Must include 33% consumers who are not affiliated with Part A service providers
- **Reflectiveness:**
  - ✓ Overall membership and PLWH membership must be reflective of the epidemic in the TGA, "with particular consideration given to disproportionately affected and historically underserved groups and subpopulations" [Section 2602(b)(1)]
  - ✓ Emphasis on race/ethnicity and gender
  - ✓ Also focus on county of residence
- Open Nominations process required
- Planning Council may not be chaired solely by an employee of the Grantee

Planning Council Roles:
As a Body and as Individuals

Individual Roles: What does it mean to be an Advocate *(informational)* and a Planner?

- **Advocates:** call attention in committee meetings to the needs of the PLWH communities they serve or represent, or to their own needs.
- **Planners:** call attention to the needs of PLWH communities other than their own or the ones they serve or represent and try to ensure decisions equitably serve all PLWH in the TGA.

PC Members as Advocates/informers and Planners

- **Often begin as Advocates:**
  - ✓ Bring passion
  - ✓ Represent our communities
  - ✓ Be heard
- **Learn to be Planners:**
  - ✓ Retain the passion
  - ✓ Continue to bring special insights and expertise
  - ✓ Consider the entire PLWH community – and specific populations other than our own
  - ✓ Listen to others/ask questions
  - ✓ Come prepared to make important decisions
  - ✓ Use data as basis for decision making

Seek Parity in Access to Services

- A key goal: seek parity (equality) in access to services for all PLWH in the TGA, regardless of:
  - ✓ Who they are
  - ✓ Where in the TGA they live
- Challenges include ensuring service:
  - ✓ Availability
  - ✓ Accessibility
  - ✓ Appropriateness

Attendance

- Select and serve on a ***"Committee of Record"***
- Participate actively on your committee
- Participate in the PSRA process annually
- Participate in ALL PC trainings
- Volunteer on Ad hoc initiatives
- Attendance requirements stated in policies

Responsibilities of Planning Council Members

- Learn the legislation
- Learn about PLWH/A needs – overall and by population group
- Be familiar with eligible services and funding sources
- Plan for *all* Ryan White-eligible PLWH/A
- Serve as link between the PC and communities

PC Responsibilities, *continues*

- Understand and help manage conflicts of interest (COI)
- Respect confidentiality
- Listen, learn, and teach others
- Keep an open mind
- Use data as the basis for decision making
- Stay focused on your responsibility for helping to develop a seamless, accessible system of care for all PLWH/A

PC Co-Chairs Roles

- Represent the PC externally
- Ensure federal mandates are met
- Advise PC and Grantee staff about PC activities and actions
- Prepare for and preside over PC and Executive Committee meetings
- Report on work of Executive Committee to full PC
- Keep membership informed

Committee Co-Chair Roles

- Serve as "administrative officer" for committee
- Propose agendas for committee meetings
- Preside over meetings
- Encourage public and member input
- Work closely with PC support & assigned Grantee staff to ensure needed information & materials are available for your meetings.
- Report committee actions and recommendations to the Executive Committee and full PC
- Ensure appropriate orientation and training for all members

Roles of Planning Council Support Staff

- Assist the Planning Council to carry out its legislative responsibilities and to operate effectively as an independent planning body
- Staff committees and Planning Council meetings
- Provide expert advice on Ryan White legislative requirements and HRSA/HAB regulations and expectations
- Oversee a training program for members
- Encourage member involvement and retention, with special focus on consumers
- Serve as liaison with the Grantee
- Help the PC manage its budget

Planning Council Operations

Planning Council:

- Must develop bylaws, policies and procedures to ensure fair, efficient operations
- Must have grievance procedures
- Must manage conflict of interest (COI)
- Should give major attention to new member recruitment, orientation and training
- Ensures that most work is done by committees and that they report through the Executive Committee to the full Planning Council
- Is assisted by Planning Council support

Expectations for Planning Council Meetings

- Public notice of meetings
- Open meetings – required by Ohio Sunshine Law
- PC decisions based on work & recommendations from committees through Executive Committee
- Parliamentary procedure followed
- Code of Conduct stated and enforced
- Public comment period
  - Managed to allow reasonable/equitable time
  - Care taken to address only issues within PC's scope of responsibility – receive and refer others appropriately
- Minutes approved and available to the public

Code of Conduct

- Address expectations around professional and courteous conduct, respect for the opinions of others, Conflict of Interest, decision making, confidentiality, and support for PC decisions
- Should be posted or otherwise available as a reminder of expectations
- Many PCs apply a similar Code of Conduct to non-members who speak during public comment periods

Conflict of Interest

Best Practices for members:

- Sign a Disclosure Form every year
- Update the form if affiliations change
- Declare any COI before discussion begins
- In decision making about priorities and allocations: answer questions but not *initiate* discussion about service categories where they have a conflict of interest
- Do not vote on priorities or allocations for categories where there is a real or perceived conflict of interest
- Do not vote on other matters where there is a conflict of interest
- Recognize and avoid the *appearance* of COI

Managing Conflict of Interest

- Planning Council must have and enforce conflict of interest policies including disclosure
- Conflict of interest occurs when a Planning Council member has a monetary, personal, or professional interest in a decision or vote
- Any member, including government agency staff, can have a conflict of interest
- Being a consumer of Part A services is not considered a conflict of interest
- Planning Council should **<u>not</u>** *discuss* particular providers and members should **<u>not</u>** *advocate* for providers

Don’ts for PC Members

- Don’t become involved in procurement
- Don’t violate – or ignore violation of – Council policies
- Don’t discuss individual provider issues – think about service categories
- Don’t focus narrowly on individual PLWH needs (not even your own) – focus on the needs of all PLWH
- Don’t make or be swayed by impassioned pleas – focus on the data
- Don’t take disagreements personally

Questions?

Section IV

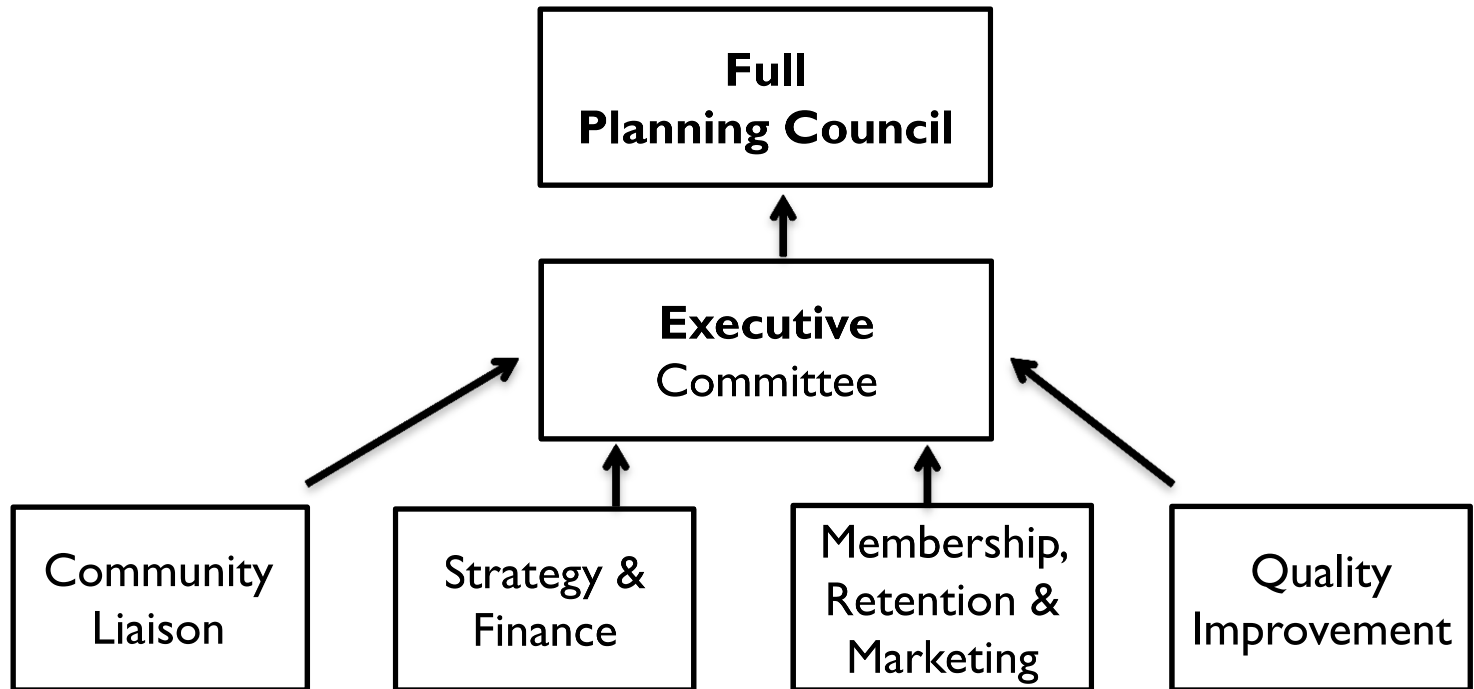
How does the Planning Council work?

Cleveland TGA PC Structure

- **PC Co-Chairs:**
  1) Cuyahoga County Representative – appointed by the County
  2) City of Cleveland, DOH Representative –appointed by the City
  3) Consumer Representative, elected by the PC
- **Executive Committee** – PC Co-chairs, and Subcommittee co-chairs
- Ad hoc Working Groups or Task Forces
- PC Staff
- PC Support/Technical Assistance Contractor

Committee Structure

Cleveland TGA Committee Operating Structure:



HRSA Expectations for Committees

- Focus on Part A legislative responsibilities
- Do groundwork for PC decision making – most of PC work is done in committees
- Have active, consistently participating members
- Have annual work plans created by committee members, with clearly assigned tasks, deadlines, and responsibilities
- Receive content and logistical support from PC Support Staff and/or Contractor.
- Receive information/reports from Grantee on regular schedule, with a defined process for requesting data

HRSA Expectations, *continues*

- Follow PC bylaws, and initiate changes where needed
- Keep minutes and make them available in a timely manner
- In implementing committee tasks:
  - Obtain and analyze data, and
  - Provide input and recommendations to full PC through Executive Committee
- Provide appropriate training for members
- Ensure diverse membership, including in terms of professional & personal backgrounds

HRSA Expectations, *continues*

- Ensure strong consumer participation on *all* committees
- Include non-PC members in committees that link to the community but not governance-related committees or Priority Setting and Resource Allocations
- Require regular attendance, Conflict of Interest disclosure and management, and adherence to Code of Conduct from *all* members

Major PC Work Products

- PSRA** – **S&F**
- Directives – **S&F**
- Open Nomination Process – **MRM**
- Ensuring Community Input/Engagement **- CLC**
- Needs Assessments/Comprehensive Planning – **QI**
- Coordination of Services/Maintaining a System of Care – **QI**
- Assessment of the Administrative Mechanism – **S&F**

PSRA Legislative Responsibility Includes:

- **Priority setting** – of allowable core medical and supportive service categories
- **Directives** to grantee on how best to meet the priorities
- **Allocation** of funds to priority service categories

PSRA
Responsibilities & Involvement

A successful PSRA process requires the active, informed involvement of :

- **People living with HIV and AIDS**, both members of the Planning Council and non-members *(consumer input)*
- The full **Planning Council**
- **Committees:**
  - Community Liaison Committee
  - Strategy & Finance *(as the lead committee)*
  - Membership, Retention and Marketing
  - Quality Improvements
- **Grantee**

Legislative Language

Planning Council will: "establish priorities for the allocation of funds within the eligible area, including how best to meet each such priority *[Directives]* and additional factors that a grantee should consider" – including:

- Size & demographics of population with HIV/AIDS
- Cost & outcome effectiveness of proposed strategies
- Priorities of the intended community
- Coordination with prevention & other Ryan White Parts
- Other funding streams
- Capacity development needs resulting from disparities in the availability of HIV-related services in historically underserved communities

HRSA Expectations for PSRA

- **PSRA = the most important PC legislative responsibility** – *full Council should participate*
- **Data-based decision making** – requires having & using appropriate epi, needs assessment, quality/outcomes, service utilization & cost data
- **Conflict of interest** disclosure and management
- **Use of clear, written procedures** – implementation must be public and fully documented, since process is subject to public scrutiny and grievances

HRSA Requirements

- At least 75% of service funds must go to core medical services
- If decision is made not to fund some core medical services, rationale needed for Part A application
- Up to 25% of funds can go to support services as approved by the Secretary of HHS
- Support services must contribute to positive clinical outcomes
- ***May seek HRSA's approval of a Core Services waiver…..***

Components of PSRA: HRSA Sound Practices

Priority Setting

- **Priority setting means determining what *service categories* are most important** for PLWH/A in the TGA
- **Do *not* consider availability of funding** – think about what services are needed by diverse area PLWH/A
- **Prioritize all service categories that *might* receive funding** – exclude those not needed in this TGA
- **Base priorities on needs of PLWH/A *in and out of care***
- **Priorities often change relatively little from year to year** *except* when legislation changes

Resource Allocation

- Process of deciding how much funding to allocate to each priority service category
- **Consider other funding streams,** since Ryan White is the payer of last resort
- **Consider costs per client per year** – allocate in dollars, and percentages
- **Some priority service categories do not receive allocations**
- **Must address unmet need** – consider costs of bringing people into care and providing care to new clients
- **Must address HIV+/unaware** (EIIHA)

Directives

- **Guidance to the grantee** on how best to meet the priorities and other factors to consider in procurement – a legislative role of the PC
- Often specify use or non-use of a particular service *model*, address *geographic or other access to services, or focus on specific populations*
- **Often have cost implications** – grantee involvement necessary for exploring costs
- Must not be so specific that they prevent open procurement
- Can be developed year round but focus usually at time of PSRA due to cost & contract implications

Core Medical Services

1. Outpatient/ambulatory medical care
2. AIDS Drug Assistance Program (ADAP)
3. Local AIDS pharmaceutical assistance
4. Oral health (dental) care
5. Early intervention services (EIS)
6. Health insurance premium & cost-sharing assistance
7. Home health care
8. Home and community-based health care
9. Hospice services
10. Mental health services
11. Medical nutrition therapy
12. Medical case management
13. Substance abuse services - outpatient

Support Services

1. Case management (non-medical)
2. Child care services
3. Emergency financial assistance
4. Food bank/home-delivered meals
5. Health education/risk reduction
6. Housing services
7. Other Professional services (Legal)
8. Linguistics services
9. Medical transportation services
10. Outreach services
11. Psychosocial support services
12. Referral for health care/supportive services
13. Rehabilitation services
14. Respite care
15. Substance abuse services – residential
16. Treatment adherence counseling

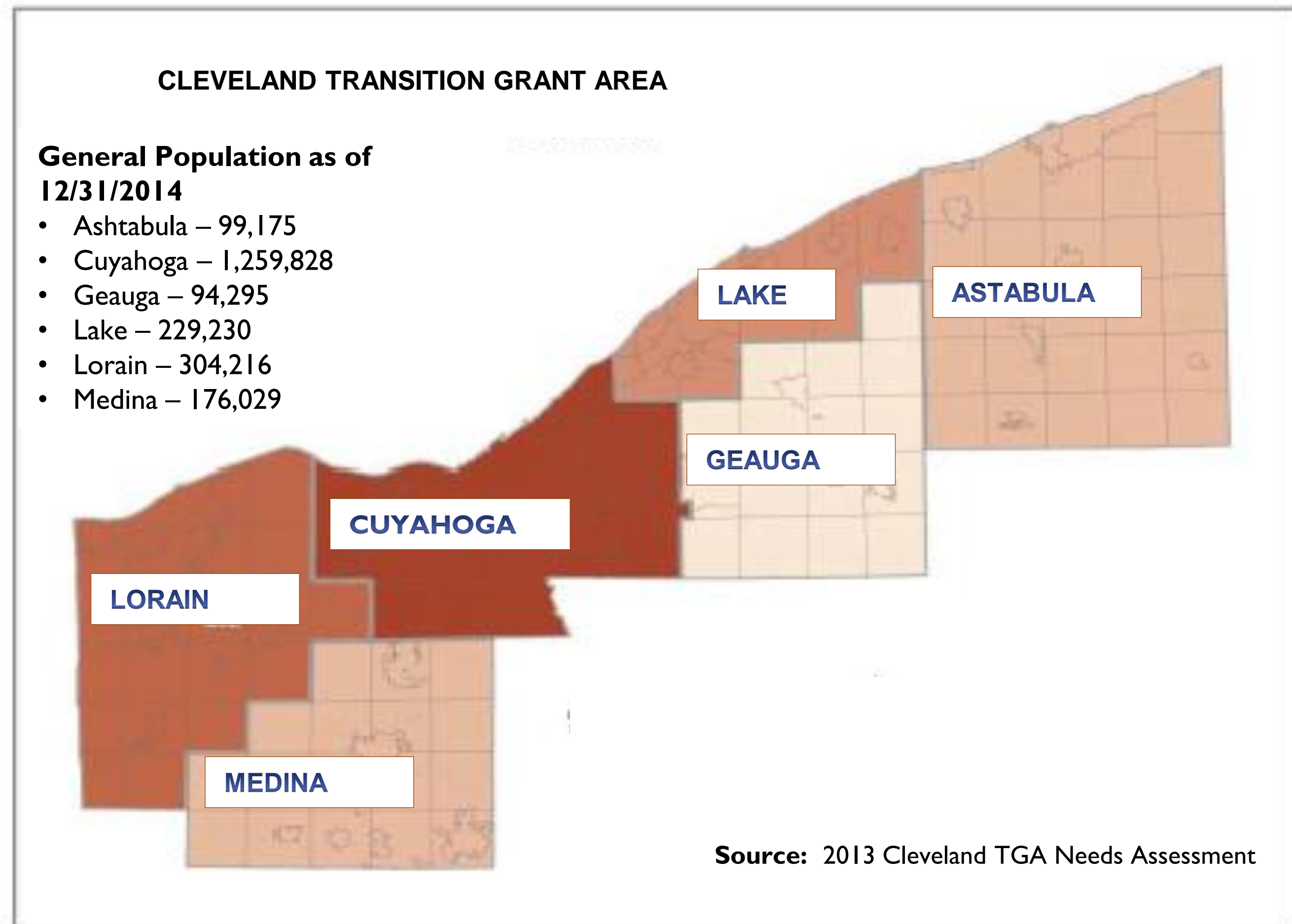
Important Resource Materials

- *Planning Council Primer* (2012) updated version
- Planning Council Operations chapter from the *Part A Manual.*
- *Cleveland TGA PC/Grantee Memorandum of Understanding (MOU).*
- *Cleveland TGA Bylaws (following final approval).*

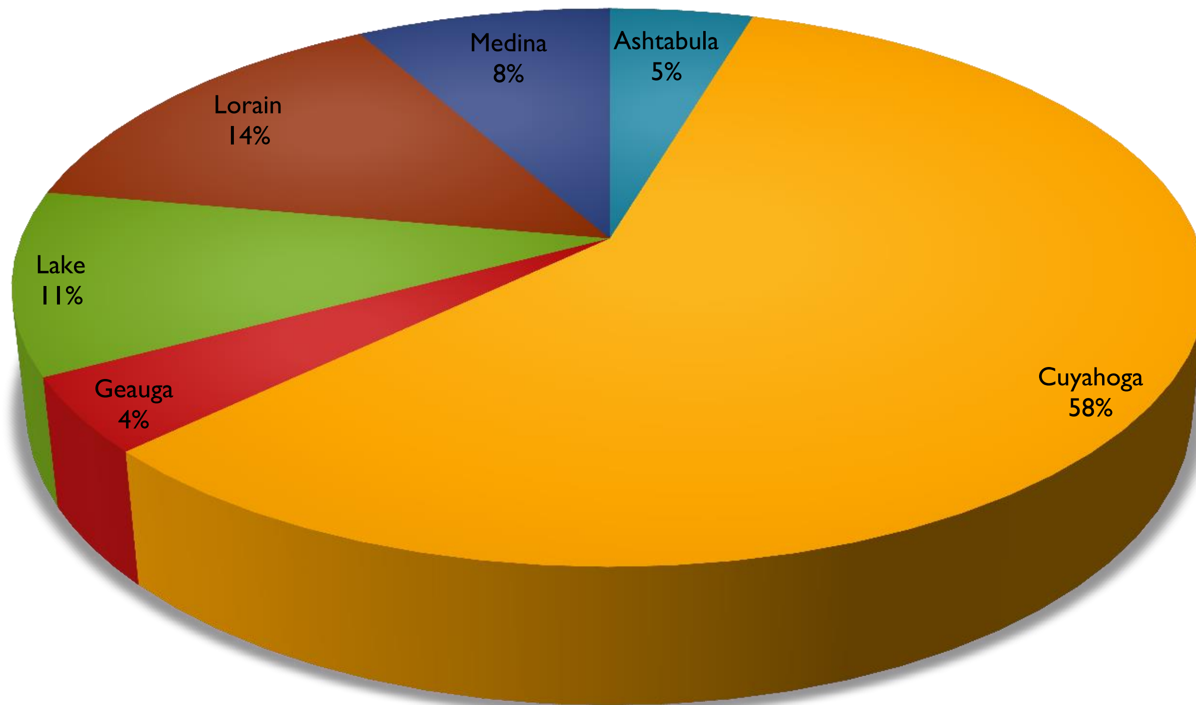
Section V

Who does this Planning Council serve, where do they live, and what do we know about them?

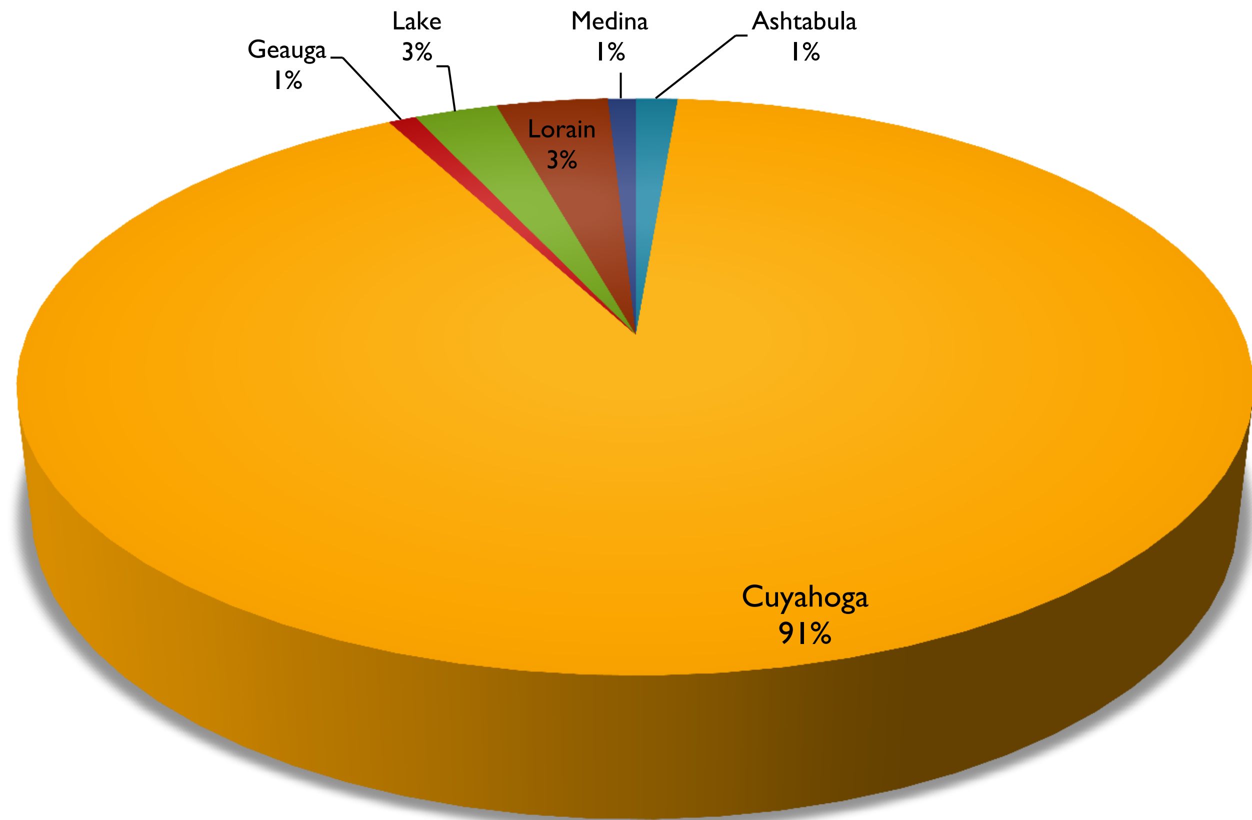
Geography of the Cleveland TGA



Cleveland TGA General Population

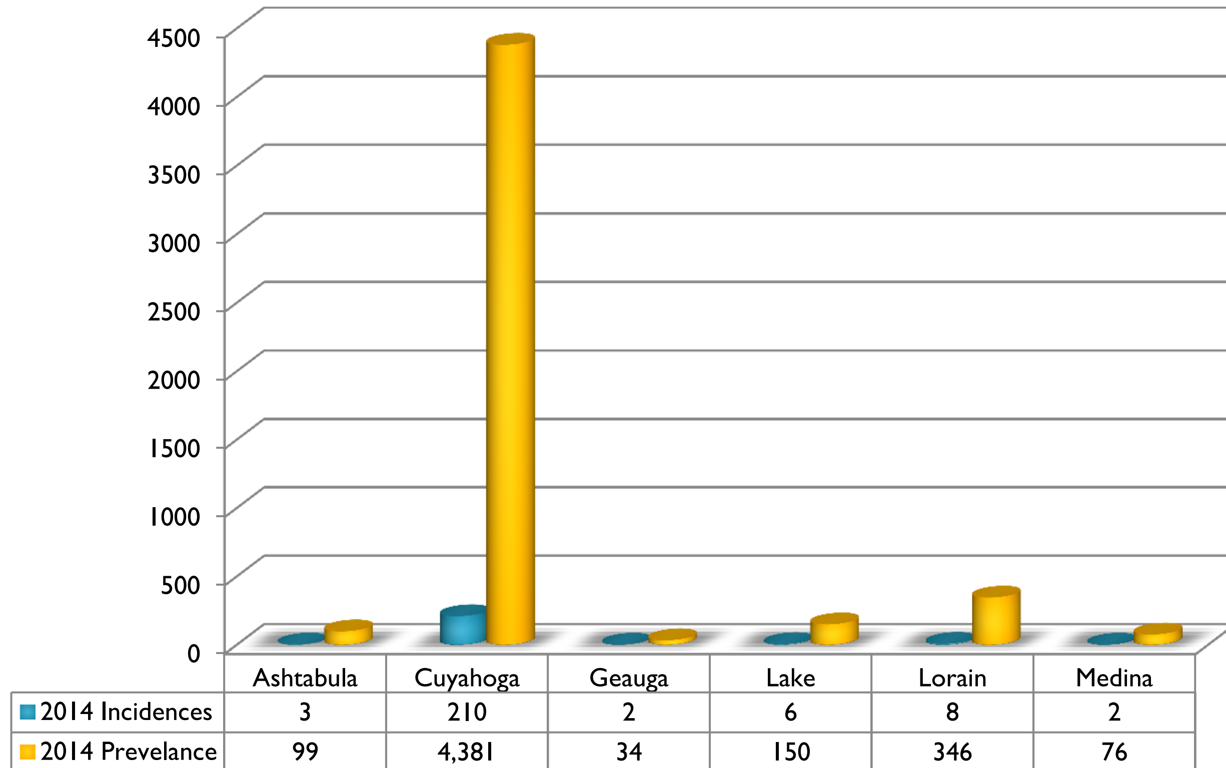


2014 HIV Incidence in the TGA



HIV Incidences vs. Prevalence of the Cleveland TGA:

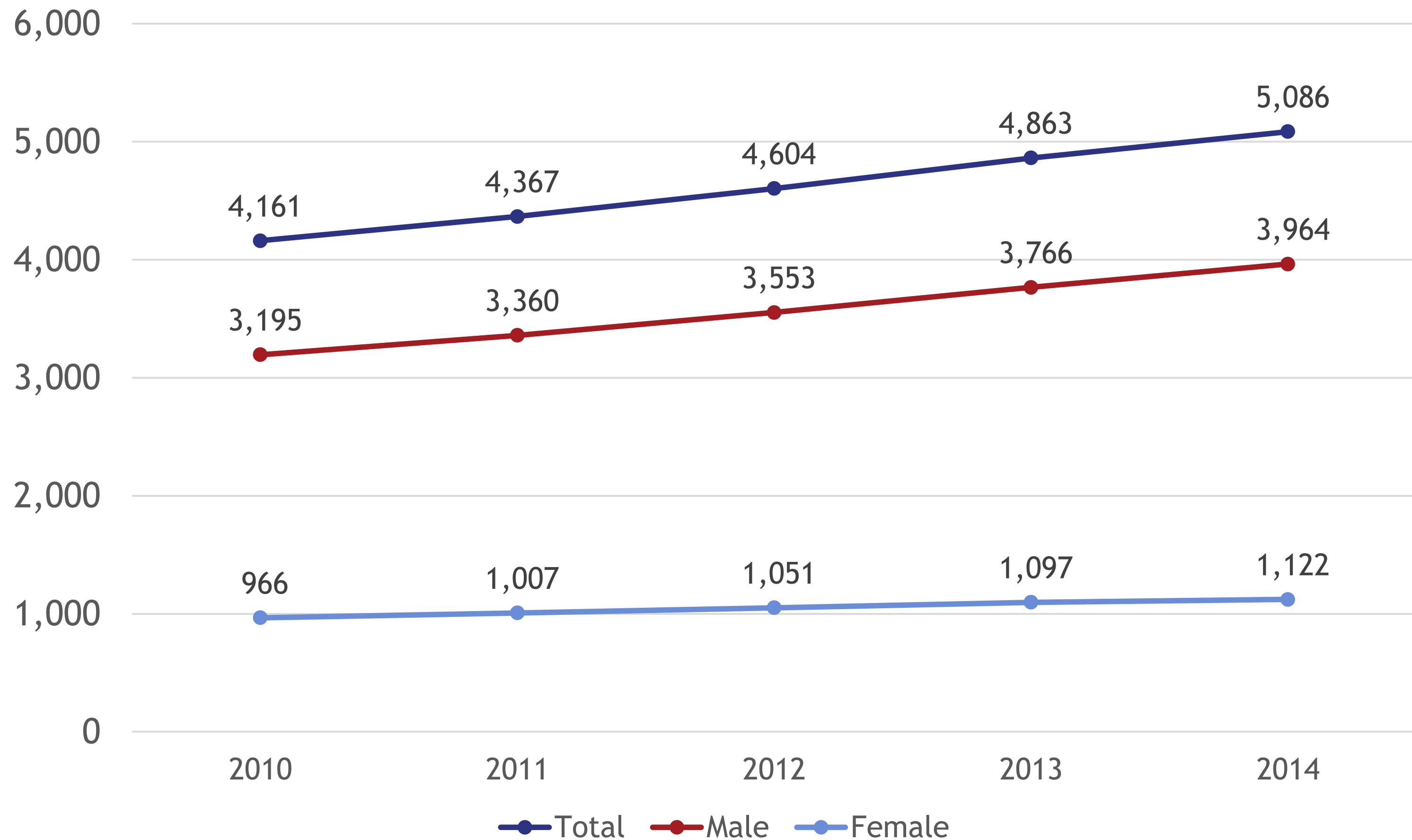
(Data reported through Dec. 31, 2014)



	Ashtabula	Cuyahoga	Geauga	Lake	Lorain	Medina
2014 Incidences	3	210	2	6	8	2
2014 Prevelance	99	4,381	34	150	346	76

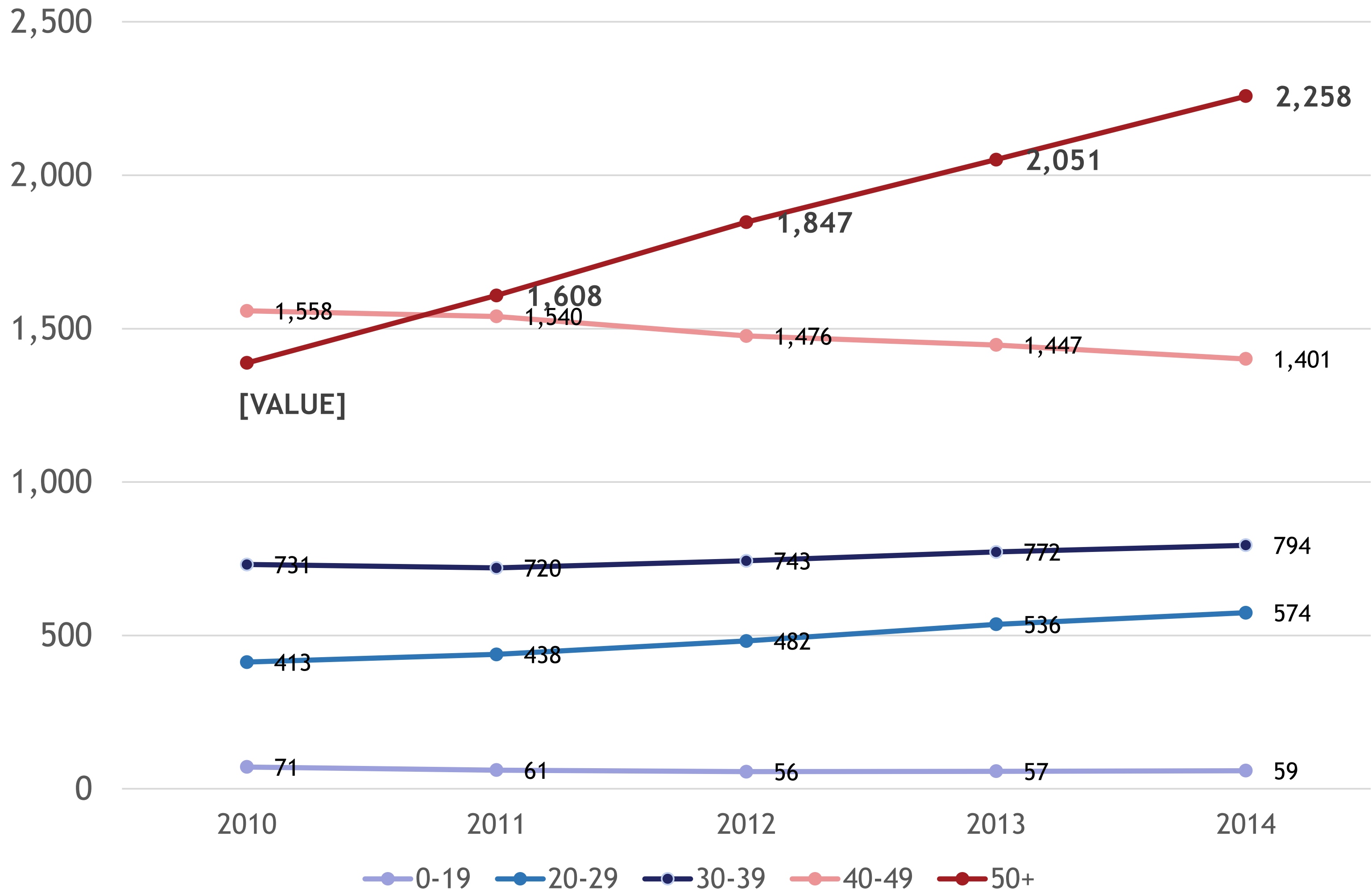
Incidence =
Prevalence =

HIV/AIDS Prevalence, by Sex Cleveland TGA, 2010-2014



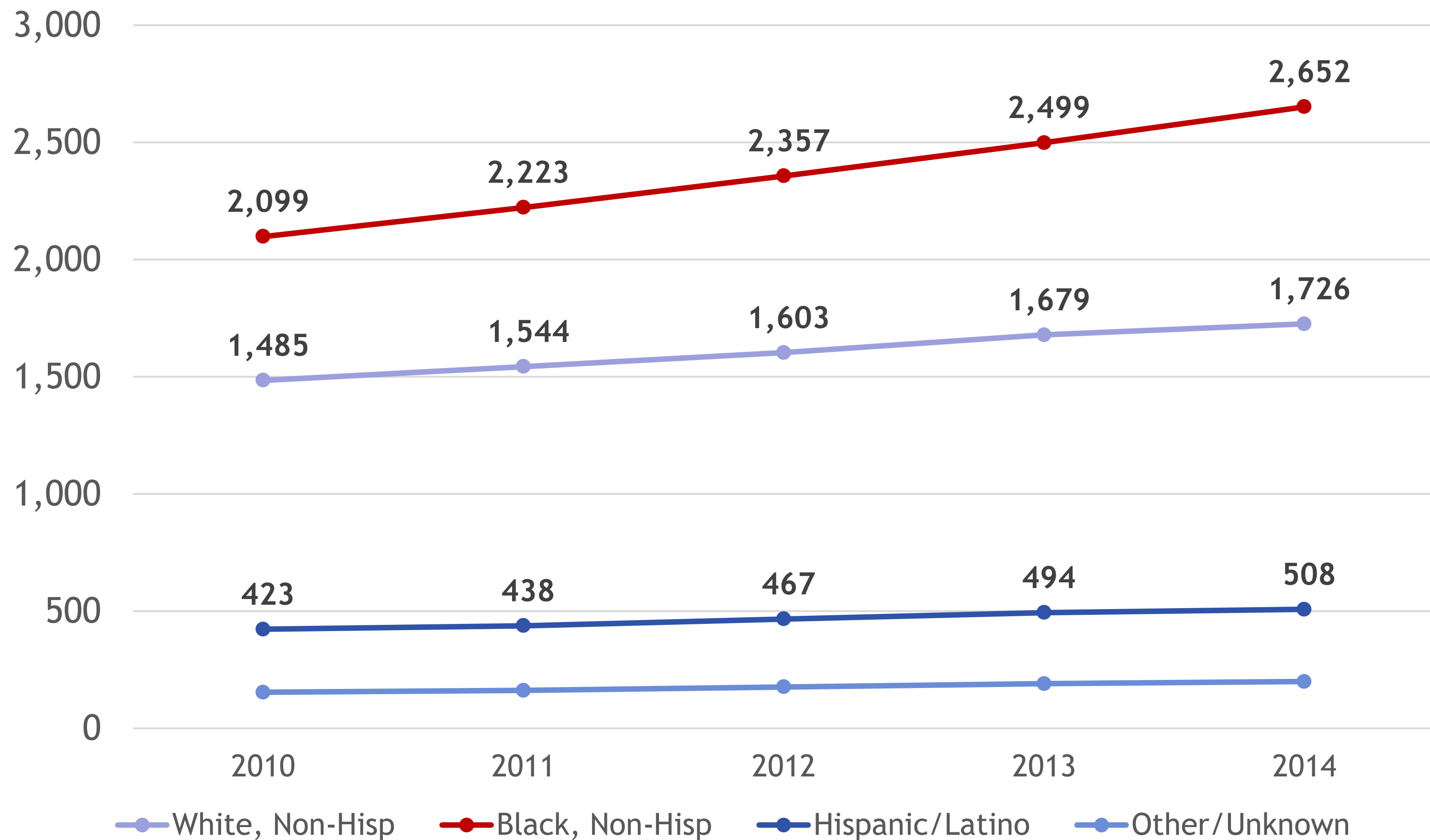
Source: Ohio Department of Health

HIV/AIDS Prevalence, by Age Cleveland TGA, 2010-2014



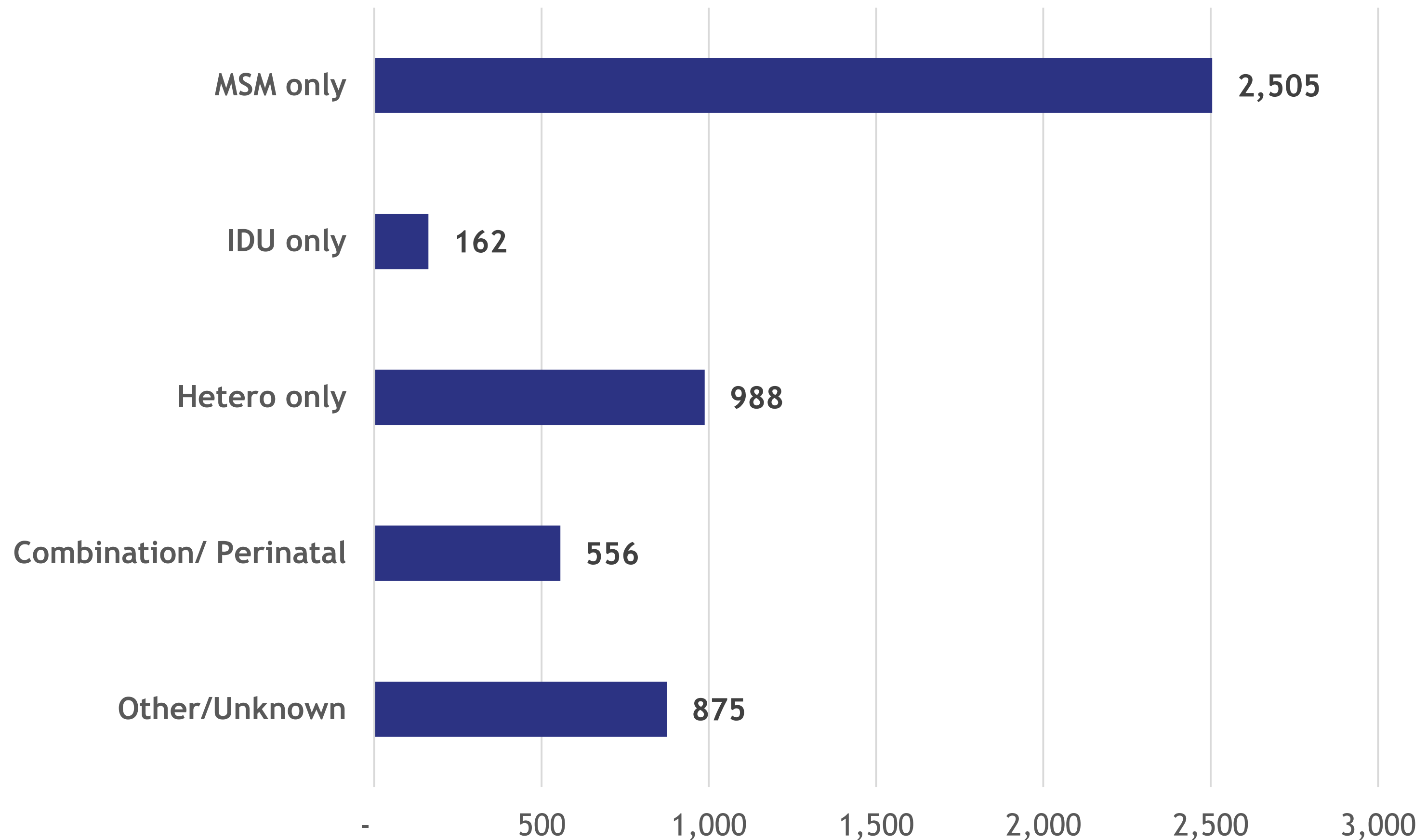
Source: Ohio Department of Health

HIV/AIDS Prevalence, by Race/Ethnicity Cleveland TGA, 2010-2014



Source: Ohio Department of Health

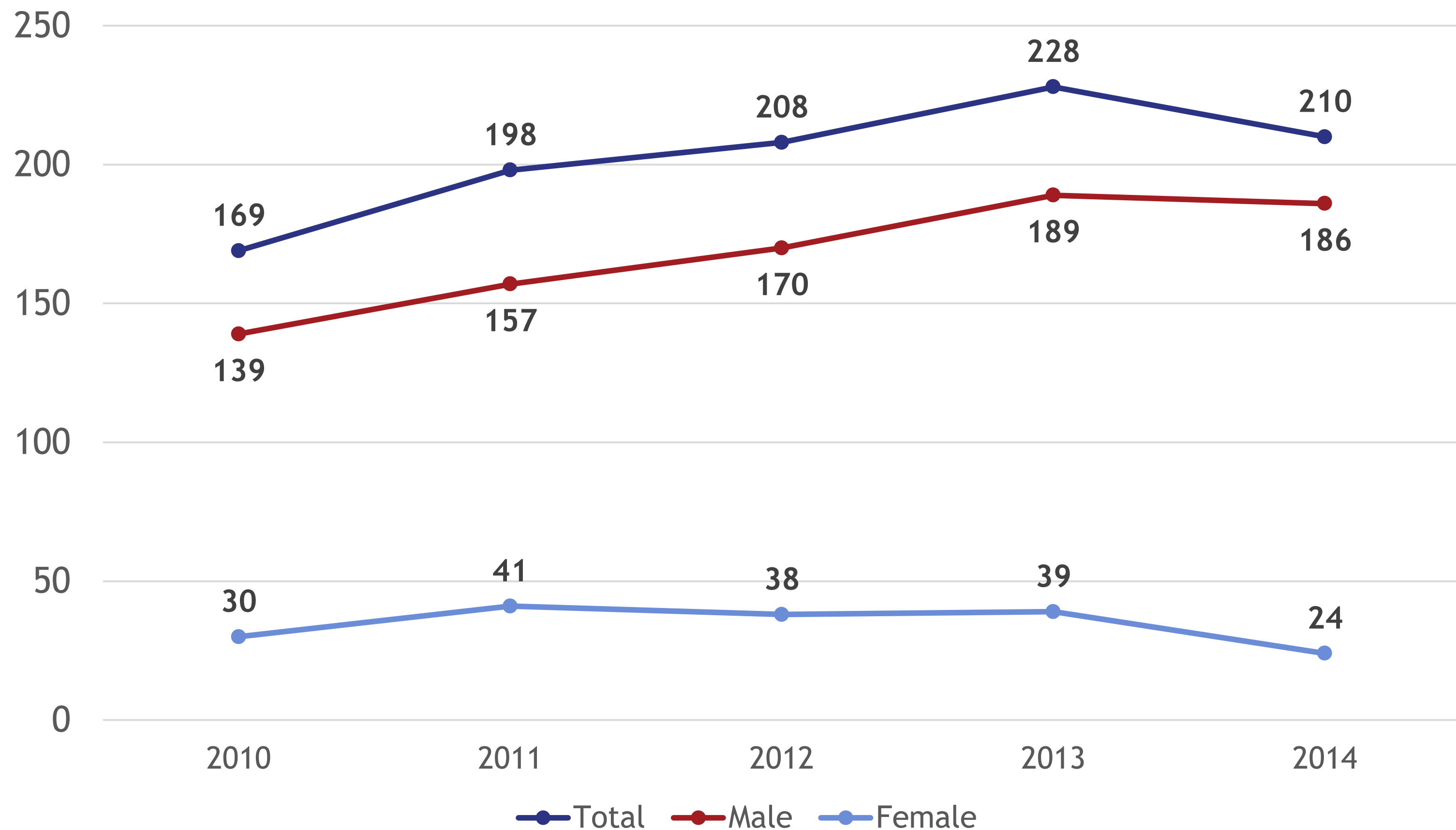
HIV/AIDS Prevalence, by Exposure Category Cleveland TGA, 2014



Source: Ohio Department of Health

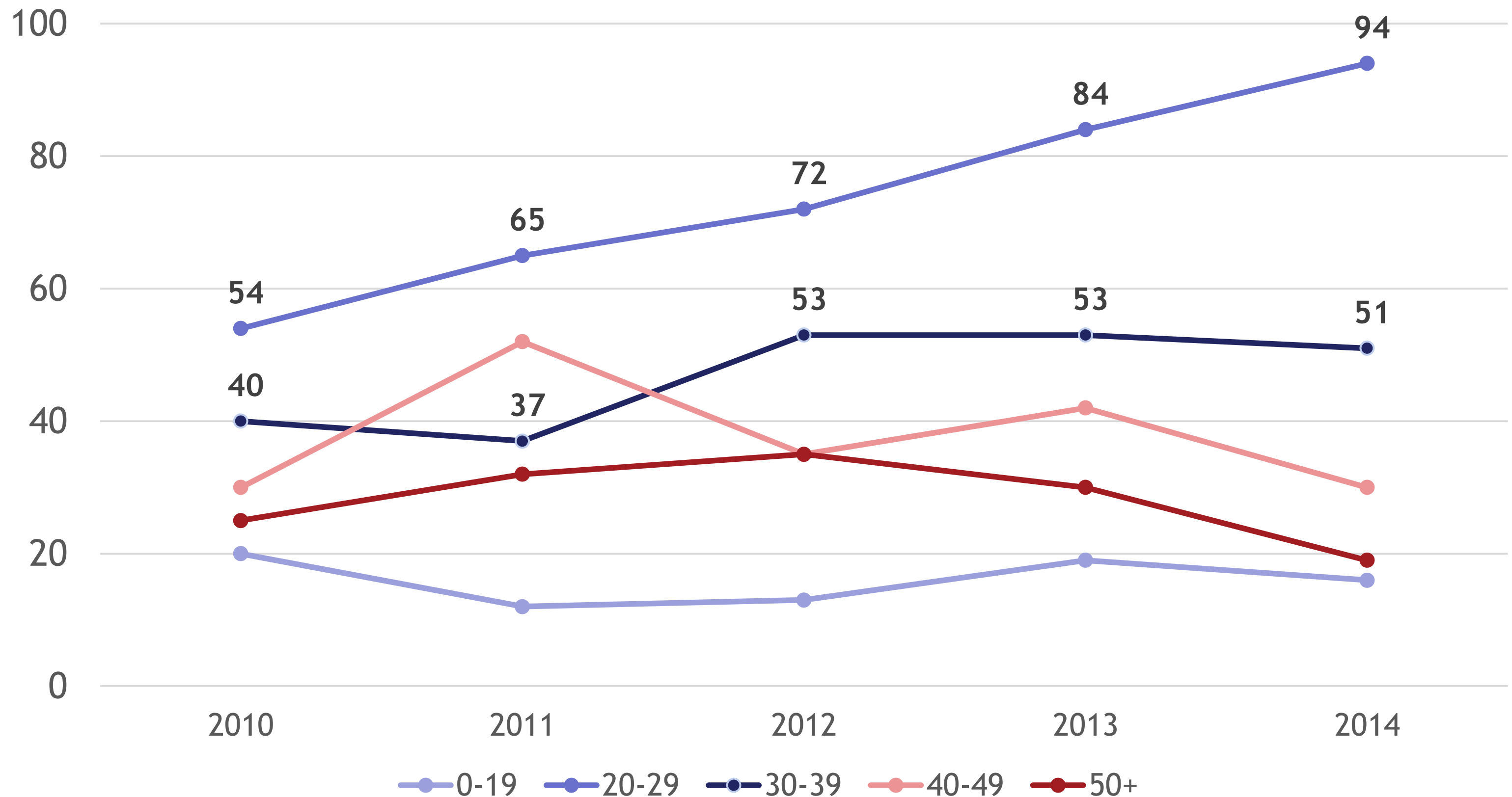
Persons Diagnosed with HIV Infection By Sex and Year of Diagnosis

Cuyahoga County, 2010-2014



Source: Ohio Department of Health

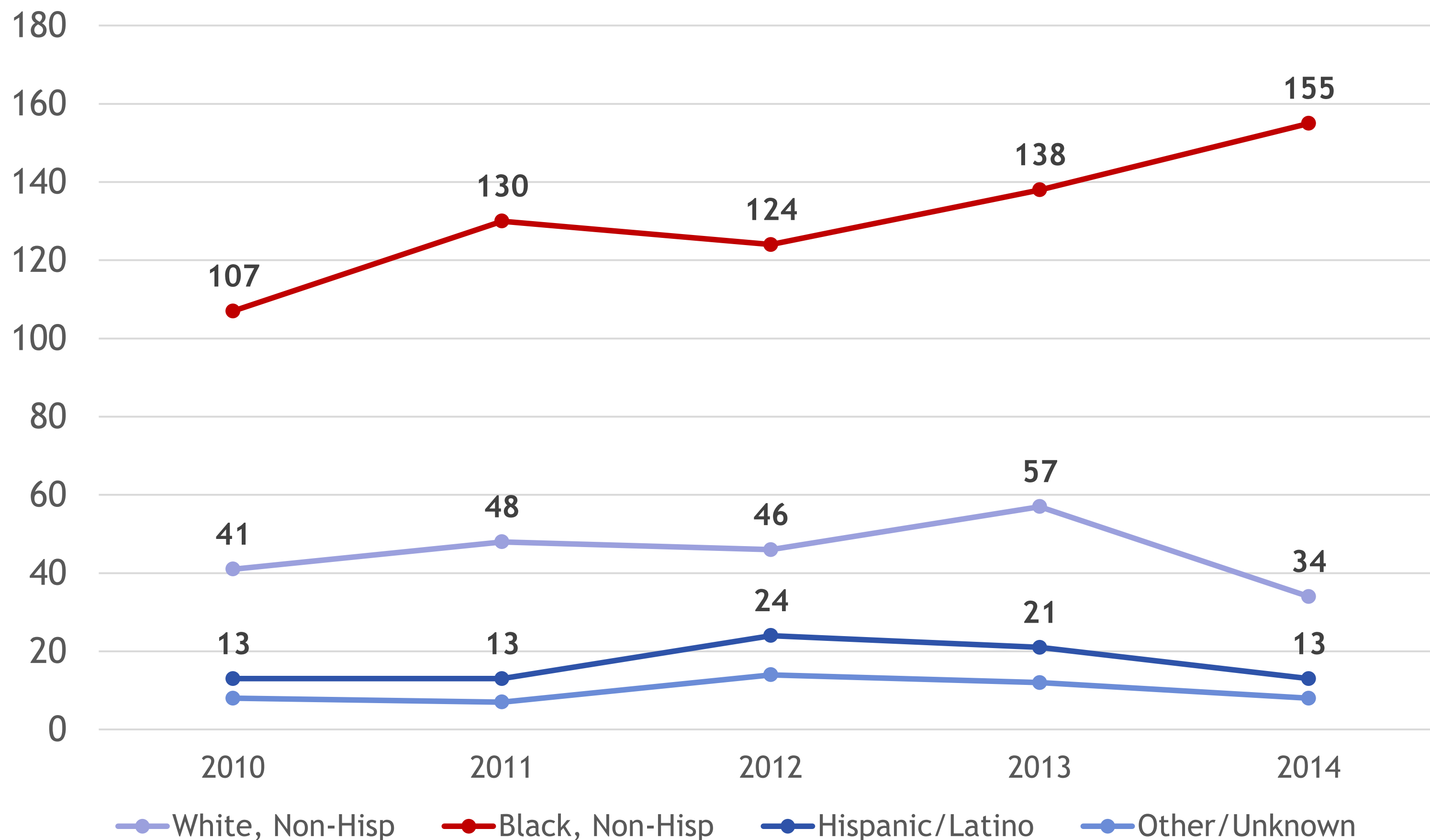
Persons Diagnosed with HIV Infection By Age and Year of Diagnosis
Cuyahoga County, 2010-2014



Source: Ohio Department of Health

Persons Diagnosed with HIV Infection By Race/Ethnicity and Year of Diagnosis

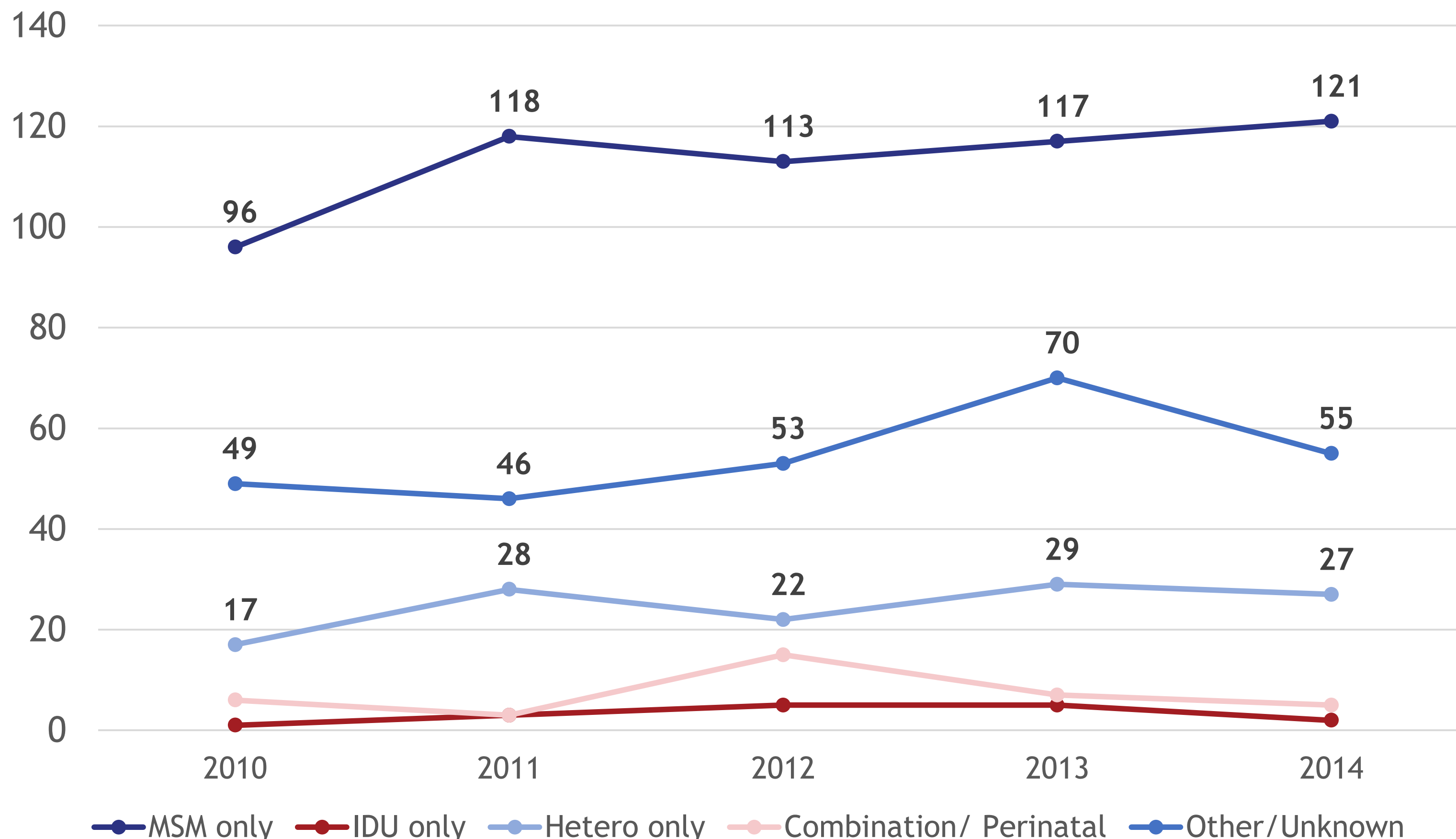
Cuyahoga County, 2010-2014



Source: Ohio Department of Health

Persons Diagnosed with HIV Infection By Exposure Category and Year of Diagnosis

Cuyahoga County, 2010-2014



Source: Ohio Department of Health

Questions/Discussions

Applying Knowledge

Applying Knowledge:
Discussion

- Among the issues Planning Councils are expected to address are **unmet need, HIV+/unaware** (Early Identification of Individuals with HIV/AIDS or EIIHA), and coordinating with other Ryan White Parts/payer sources to ensure PLWH access to care.
- **How can each of these issues be addressed as part of the PC roles and responsibilities in the matrix seen earlier in the training?**

(Discuss in your group and be prepared to share)