LET'S MEET IN THE MIDDLE

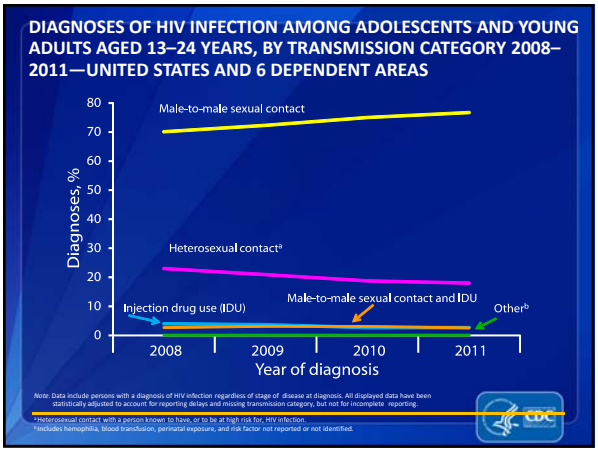
ENSURING OPTIMAL ENGAGEMENT AND RETENTION IN CARE FOR HIV INFECTED ADOLESCENTS

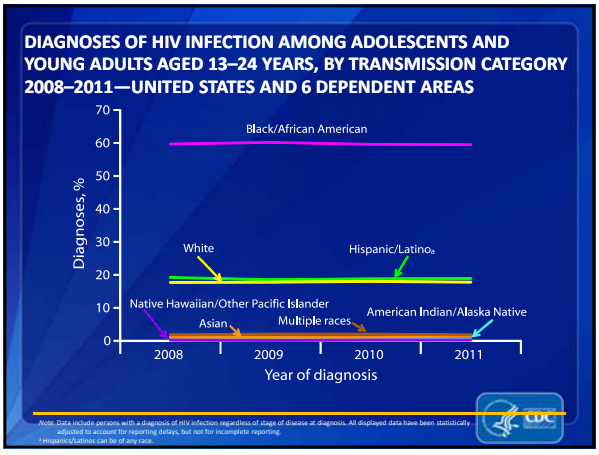
OVERVIEW

- Defining the population (and the problem)
- Linkage, engagement, and retention in care
- Transition plans
- Social media

WHAT IS A "YOUTH?"

- Definition
  - : the time of life when one is young; *especially* : the period between childhood and maturity
  - the early period of existence, growth, or development
- Age range typically considered **13-24** years





THE FACTS

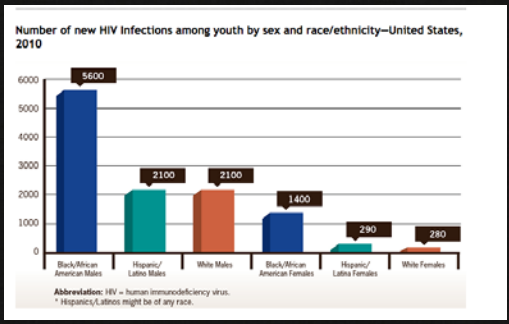
1 in 4 new HIV infections occurs in youth ages 13 to 24 years

About 12,000 youth in 2010, or about 1,000 per month, were infected with HIV

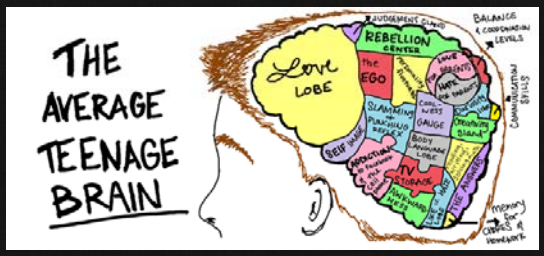
About 60% of all youth with HIV do not know they are infected, are not getting treated, and can unknowingly pass the virus on to others

CDC Vital Signs, HIV Among Youth in the US, November 2012

WHO'S AT RISK?



WHERE DOES HIV CARE FIT IN?



DEFINING LINKAGE TO, RETENTION, AND ENGAGEMENT IN CARE

- Linkage to care: entry into outpatient care after HIV diagnosis
- Retention in care: the continuous involvement in outpatient care over time
- Engagement in care: the distinct but interrelated processes of linkage to and retention in care

DISPARITIES IN ENGAGEMENT IN HIV CARE

- Younger age is associated with lower rates of retention in care during the first two years following diagnosis
- 15% of persons age 25-34 years with suppressed viral load

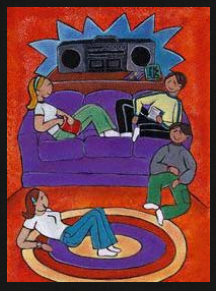
Hall HI, et al. JAMA Intern Med 2013; Ulett, et al. Aids Patient Care and STDs 2009

PATIENT, PROVIDER, AND SYSTEM FACTORS AFFECTING YOUTH ENTRY INTO CARE

- Negative experience at testing site
- Fear of disclosure, discrimination, and stigmatization
- Distrust of healthcare system/providers
- Gaps in follow-up/referral services
- Lack of motivation, denial
- Lack of comfort navigating healthcare system
- Financial barriers, lack of insurance

Garland, PM et al. AIDS ED Prev, 2011, 23; 117-127

WHERE WOULD YOU RATHER BE?



FACTORS AFFECTING RETENTION IN CARE

- Alcohol/substance use
- Mental health needs
- Socioeconomic factors
  - Housing, employment, transportation
- Negative experience or no experience navigating the healthcare system
- Stigma, discrimination, and disclosure
- Lack of a support system

THE YMSM OF COLOR SPNS INITIATIVE

- **The Initiative funded in Fall 2004, with five year grants**
  - DHHS Health Resources Services Administration – SPNS
  - The initiative completed its 5 year cycle
  - 8 demonstration sites and a TA and evaluation center (GWU YES Center)
- **Demonstration site grantee goals**
  - Develop, implement, and evaluate innovative models of care for YCMSM
  - Apply intervention models that identify, engage, link, and retain HIV-infected individuals in care

YCMSM SPNS INITIATIVE GRANTEE SITES

SPNS SITES

STUDY PARTICIPANT RESULTS

Variable N= 363	Outcome	
Age	20.4 , SD=1.9	Range =15-24
Age at HIV Diagnosis	19.9, SD=2.2	Range 9-25
Initiated MSM Sex	14.5 , SD=3.2	Range 4-21
Race	African American =242	67%
Gay/homosexual identified	N=231	64%
Education	high school education Attended college	71% 43%
Employment	Employed = 162	46%

LINKAGE TO CARE

- **334** patients included in the linkage analysis
  - 72% (n=239) of YCMSM were linked to care within 30 days
  - 81% (n=270) within 60 days
  - 87% (n=291) within 90 days of their HIV diagnosis
- No client-level characteristics were associated with early linkage
- If the person who provided the positive test result referred the participant to care, specifically if he or she called to make the appointment, linkage to care was earlier

Hightow-Weidman et al. 2011

RETENTION IN CARE

- Most (83%) of the YCMSM were retained in care after 12 months
- 74% of the YCMSM who were started on antiretroviral therapy (ART) achieved an undetectable viral load (< 400) during the study

Hightow-Weidman et al. 2011

RETENTION IN CARE

- Most sites had a small number of dedicated providers who were actively engaged in the initiative and responsible for providing quality care to youth in an ongoing fashion
- All sites used clinic appointment reminders and some form of case finding for patients who had missed appointments (typically in the form of telephone calls, texts, e-mails, or in rare cases, home visits)
- Patients at the sites with youth specific support groups and social events showed higher retention

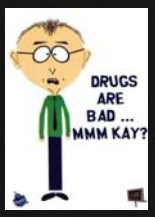
Hightow-Weidman et al. 2011

SUBSTANCE USE AMONG HIV+ YMSM IN NORTH CAROLINA

Substance use last 30 days	STYLE (N=81)	healthMpowerment (N=21)	SNAP (N=20)
Alcohol	45 (55.6%)	19 (90.5%)	17 (85%)
Binge alcohol once a week or more	----	3 (14.3%)	8 (40%)
Marijuana	34 (42%)	7 (33.3%)	13 (65%)
Cocaine	12 (14.8%)	1 (4.8%)	6 (30%)
Amphetamines/ Stimulants	3 (3.7%)	0 (0%)	1 (5%)
Prescription meds	13 (16.0%)	1 (4.6%)	4 (20%)

ASK ABOUT SUBSTANCE USE AND PROACTIVELY ADDRESS

- Talking to youth about substance use must be:
  - Safe
  - Judgment free
  - A conversation



STRATEGIES FOR ADHERENCE IN CONTEXT OF DRUG/ALCOHOL USE

- Create a plan for taking meds when drunk or high (or planning to get there)
  - Move medication does ahead a few hours
  - Set reminder in phone or ask a friend you trust to remind you to take
- Carrying "emergency" stash of medications in case plans change
  - Discrete pill case/container

CRITICAL ROLE OF PSYCHOSOCIAL FACTORS IN ENGAGEMENT IN CARE

- High rates of negative affective states, such as depression and anxiety
- Poorer psychological functioning can result in decreased quality of life, impaired social functioning, decreased ART adherence and associated with increased participation in sexual and substance use risk behaviors
- HIV+ LGBT youth often have unique mental health needs because they may face rejection by peers and family, severely limiting social supports

Hosek et al. 2000; Murphy et al. 2001; Hosek et al. 2005; Murphy et al. 2001

EXPERIENCES OF SEXUALITY-RELATED HARASSMENT

- 74.1% of men reported being made fun of or called names
  - 55% reported this experience to be stressful
- 58% reported being treated rudely or unfairly
  - 62% reported this experience to be stressful
- 16.2% reported being hit or beaten up
- Significant association between experiencing a high level of sexuality-related bullying and depressive symptoms, having attempted suicide, and reporting parental abuse

Hightow-Weidman et al. 2011

FINANCIAL INSTABILITY: SPNS Cohort

How often did you run out of money for basic needs in the last 3 months?	Many times: 110 (32.0%) A few times: 83 (24.1%) Once or twice: 77 (22.4%)
How often did you have to borrow money to get by financially in the last 3 months?	Many times: 74 (21.5%) A few times: 78 (22.7%) Once or twice: 107 (31.1%)
Currently employed	162 (45.6%) of those with job mean hours worked last week=30.5

Hightow-Weidman et al. 2011

STRATEGIES FOR PREVENTING HIV TRANSMISSION FROM SEXUALLY ACTIVE, HIV+ YMSM TO THEIR PARTNERS

Strategies to Identify *Undiagnosed* HIV-Positive YMSM

- Promote more frequent HIV testing and counseling (individuals, couples)
  - Client-initiated voluntary counseling and testing
  - Provider-initiated HIV testing
  - HIV testing and counseling in health clinics
  - Venue-based outreach and mobile HIV counseling and testing

Strategies to Prevent Transmission for *Diagnosed* HIV-Positive YMSM

- ART initiation
- Adherence counseling and support
- STI diagnosis and treatment
- Partner testing and disclosure
- Condom distribution and provision
- Risk reduction counseling (eg, for sexual or drug-related behaviors)
- In serodiscordant partnerships
  - ART initiation (consider regardless of CD4 cell count or stage)
  - Partner disclosure
  - Risk reduction counseling with condom distribution

Adapted from Fenton KA. *Sex Transm Infect.* 2010;86:2-4.

PROVIDE COMPREHENSIVE WELLNESS

- Focus on the whole person (not just the HIV part)
- Plan to support men throughout their lifetime
- Operate from an "asset" rather a "deficit" model (resiliency)
- Include enhanced access to mental health services and substance use treatment
- Encourage network (mothers, other caregivers, friends, partners) participation in care

CREATING A "YOUTH FRIENDLY" CLINIC ≠

CREATING A YOUTH FRIENDLY CLINIC

- Friendly and warm staff
- Materials that are relevant
  - (e.g. Have posters and flyers with same-sex couples and transgendered youth)
- Flexibility (drop in hours, night hours)
- Actively **involve** young people in program design and delivery

MULTIDISCIPLINARY CLINICS

- Reducing the need to navigate complex healthcare systems and improves coordination of services
- Can facilitate access to youth-focused medical and social services

Davila JA et al. AIDS Care, 2013;

MODELS OF CARE

Pediatric Model	Adult Model
Family-centered approach	Patient-centered approach
Concentration on health maintenance	Concentration on disease management
Focus on growth and development	Focus on progressive decline
Prescriptive approach (the practitioner is responsible for the course of treatment)	Collaborative approach (the practitioner and the patient are responsible to each other for the course of treatment

Adapted from "**HIV Care for Youth, Transitioning Care Module.**" Available at: http://www.hivcareforyouth.com/

ENSURING A SMOOTH TRANSITION

Pediatric/Adolescent Clinic

- Warm, nurturing, inviting

Adult clinic

- Impersonal, cold, confusing

TRANSITION PLAN

- Collaborative approach between adolescent/pediatric care and adult services
- Considerations
  - Age: What is optimal age?
  - Length: Over how long a time period should transition occur?
  - Route of infection- Perinatally infected youth may have different needs than behaviorally infected youth.

PRIOR TO TRANSITION

Does the youth:

- Know when to seek medical care for symptoms or emergencies?
- Identify symptoms and describe them?
- Make, cancel, and reschedule appointments?
- Arrive at appointments on time?
- Call ahead of time for urgent visits?
- Request prescription refills correctly and allow enough time for refills to be processed before medications run out?
- Negotiate numerous practitioners and subspecialty visits?
- Understand entitlement programs (if needed) and know how to access them?

SUCCESSFUL TRANSITION INVOLVES A PATIENT-TAILORED PROCESS; IT IS NOT A ONE-TIME EVENT.

THE TRANSITION PROCESS SHOULD ENHANCE YOUTH AUTONOMY, CULTIVATE A SENSE OF PERSONAL RESPONSIBILITY, AND FACILITATE SELF-RELIANCE.

empowerment
noun | enabling, equipping, emancipation, enfranchising

- give them some control over their lives (e.g. starting meds)
- allow decision making partnerships (e.g. choice of medications)
- reward/motivate for positive behaviors (e.g. viral suppression, coming to clinic on time)

USING TECHNOLOGY TO ENGAGE AND RETAIN YOUTH IN HIV CARE

STAYING CONNECTED

TECHNOLOGY IS PERVASIVE

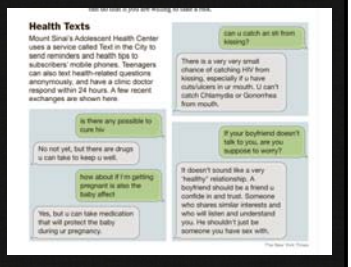
- 91% of US adults own a cell phone (Sept 2013)
  - Among adults age 18-29 years
    - 97% text
    - 84% access the internet on their phones
    - 73% send or receive email
    - 77% download apps
    - 40% participate in video chats

Pew Internet and American Life

ANYTHING PAPER WILL BE "LOST" BEFORE EVEN LEFT CLINIC

- Paper-free culture
- Patient transience, shared living spaces, lack of confidentiality
- Take advantage of cellphone to:
  - Program important numbers (nurse, social work, ADAP pharmacy)
  - Make and record follow-up appointments before they leave

TEXTING



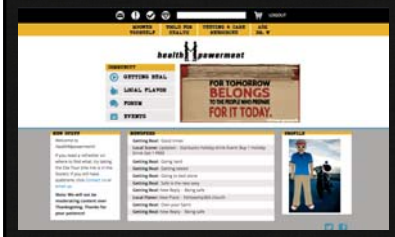
CONNECTING WITH SOCIAL MEDIA

INTERNET AND SOCIAL MEDIA BASED INTERVENTIONS

USE OF M-HEALTH FOR PREVENTION

- Why Mobile?
  - Reach
  - appeal
  - low cost
  - accessibility in time and space/privacy
  - delivery of personally tailored information
  - interactivity

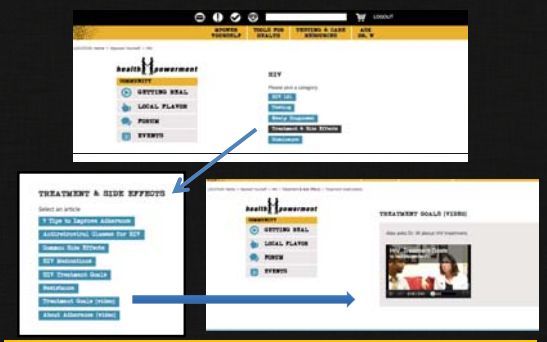
HEALTHMPOWERMENT



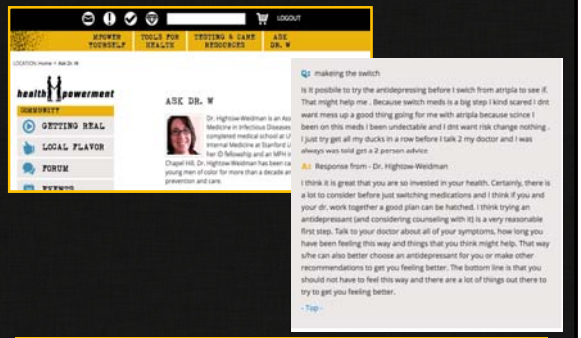
Computer

Mobile phone

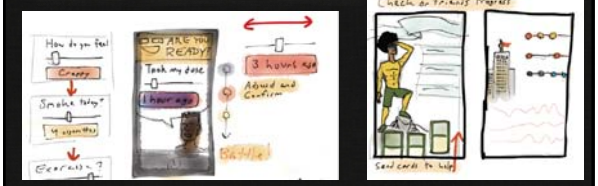
MPOWER YOURSELF



CONNECTION TO CARE: ASK DR. W



Medtropolis



IT'S A PROCESS, NOT A DESTINATION

- **Respect**
  - care about them as people, not patients
  - No B.S.
  - don't judge --- listen
- **Communication**
  - you must understand each other
  - tone down medical jargon, but don't patronize
  - consider use of technology
- **Cultural competence**
  - Ask, learn, empathize