## Gender affirmation

An empowerment approach to addressing transgender health disparities



Social and Behavioral Science Research Network National Scientific Meeting October 25 – 26, 2017



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## HIV-related disparities among transgender ('trans') women

- » 34 times higher odds of infection than general population in U.S.<sup>1</sup>
- » Highest percentage of newly identified HIV cases <sup>2</sup>
- » Almost 3x higher community viral load than nontrans adults in San Francisco 3
- » African-American transgender women are disproportionately affected <sup>4,5</sup>

### HIV treatment-related disparities

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- » Trans women living with HIV are less likely to take antiretroviral therapy (ART)<sup>6</sup>
- » Those who do initiate ART:
  - have lower rates of medication adherence
  - report lower self-efficacy for integrating ART into daily routines
  - report fewer positive interactions with health care providers than non-trans adults <sup>7</sup>

### Trans women and pre-exposure prophylaxis (PrEP)

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- » Low levels of awareness, even in areas with stronger medical and social supports <sup>9</sup>
- » No trans-specific guidance for implementation
- » Low levels of enrollment and retention in demonstration projects <sup>10</sup>
- » Rarely included in observational studies, rarely disaggregated <sup>11,12</sup>
- » Of the existing clinical trials, iPrEx is the only one with confirmed enrollment of trans women <sup>13</sup>

#### Trans women in iPrEx

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- » Of the 2499 participants:
  - 29 (1%) identified as women
  - 296 (12%) identified as "trans"
  - 14 (1%) reported use of feminizing hormones
  - 339 (14%) reported one or more of these characteristics.
- » Among trans women:
  - 11 HIV infections in the active arm
  - 10 in the placebo arm
  - Hazard ratio of 1.1 (95% CI: 0.5 to 2.7)

#### » Zero effectiveness on an intention to treat basis

» Those on hormones were less likely to have protective PrEP drug levels than those not on hormones <sup>14</sup>



Transgender women have highest rates of HIV of any group

#### Impact on Services:

Prevention and treatment programs are based on MSM-specific data

#### Trans invisibility perpetuates health disparities

These rates are included in rates of **HIV among MSM** 

#### Impact on Research:

We know LESS than we think we do about what works for trans women

#### **\$\$\$ is allocated** to research and

services for MSM based on these rates

## **Trans-specific** barriers and facilitators to HIV treatment engagement, PrEP uptake, and medication adherence

Barriers	Facilitators
Avoidance of healthcare due to stigma and past negative experiences	Access to gender affirming, trans-informed health care
Prioritization of transition-related healthcare (e.g. hormones, surgery)	Integration of hormone therapy and HIV treatment or PrEP provision
Concerns about adverse interactions between antiretrovirals (HIV tx or PrEP) and hormone therapy <sup>8</sup>	Education about ART and PrEP from trusted sources, such as trans peers <sup>14</sup>

#### Importance of/ Need for gender affirmation

#### Satisfaction with/ Access to gender affirmation

Desire for transitionrelated procedures

Desire to be affirmed as female

Desire to "pass" or "live stealth" Gender affirming health care

Affirming relationships: Family, peers, and/or lovers and sex partners

Ability to "pass"

## ACCESS to gender affirmation



#### **Model of Gender Affirmation**



**Objectification Theory** 

(Fredrickson and Roberts 1997; Moradi and Huang 2008) Identity Threat Model of Stigma

(Major and O'Brien 2005)

Oppression and Sex in High Risk Contexts

(Diaz et al. 2001, 2004)

### Gender affirmation, depression and ART adherence (n=861)

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	Depression				
	OR	95% LCL	95% UCL	р	
Importance/need for gender affirmation	1.142	1.015	1.286	0.0279	
Satisfaction/access to gender affirmation	0.717	0.62	0.829	<.0001	
Body satisfaction	0.668	0.575	0.775	<.0001	

	Adherence to ART				
	OR	95% LCL	95% UCL	р	
Depression	0.609	0.379	0.977	0.0398	

# Gender affirmation, retention in care and viral suppression (n=861)

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	Retention in care			
	OR	95% LCL	95% UCL	р
Satisfaction/access to gender affirmation	1.262	1.073	1.484	0.005
Body satisfaction	1.336	1.129	1.581	0.0008

	Viral suppression				
	OR	95% LCL	95% UCL	р	
Importance/need for gender affirmation	1.144	1.012	1.293	0.0318	
Satisfaction/access to gender affirmation	1.161	1.012	1.333	0.0335	

#### Effects of Gender Affirmation

## Gender affirmation needs met

(hormones/ surgery, social affirmation) Decreased depression <sup>16</sup> Improved health, quality of life <sup>17</sup>

Decreased sexual risk <sup>18</sup>

#### **Resilience / Protective Factors**

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# Gender affirmation - operationalized

Sessi on	Торіс	Sample Objectives
1	Gender Pride	<ul> <li>Explore and discuss trans identities and historical figures</li> </ul>
		• Explore values, decision, and relational contexts unique to trans women's lives
2 Looking Good, Feeling Good	<ul> <li>Discuss gender affirmation and how it affects self- image, self-care and power to negotiate safer behaviors</li> <li>Discuss transition-related health care</li> </ul>	
	<ul> <li>Explore connections between self-care and feeling good</li> </ul>	
3	Let's Talk about Sex	<ul> <li>Provide accurate information on HIV/STIs</li> <li>Discuss protection strategies of oneself and one's partners</li> </ul>
4	Taking Back the Power	<ul> <li>Explore the impact of transphobia on one's sense of personal power</li> <li>Discuss assertiveness skills, basic self-defense information</li> </ul>



Pilot RCT (n=89)







Intervention to optimize engagement in HIV care and medication adherence among HIV+ transgender women



6 sessions with peer educator, 1 group workshop

Multi-site RCT: UCSF and Friends Research Institute (LA)

Funded by NIH/NIMH R01MH106373 (PI: Sevelius), California HIV/AIDS Research Program IDEA award, UCSF Academic Senate Individual Investigator Grant 555242-34935, CAPS Innovative Award







Trans Research Informed communities United in Mobilization for the Prevention of HIV

- » First PrEP demonstration project initiative to focus on trans communities
- » Funded by California HIV/AIDS Research Program (CHRP) (PI: Sevelius)
- » Model of Gender Affirmation as conceptual framework, utilizes community mobilization strategies
- » Clinical sites:
  - La Clinica de la Raza, Oakland
  - Gender Health Center, Sacramento



## The Power of Being Seen

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Context Matters: Addressing The Social Environment to Improve 90-90-90 in sub-Saharan Africa

Sheri A Lippman CAPS/Medicine, UCSF University of the Witwatersrand, RSA

SBSRN, San Francisco 2017



# Social Epidemiology

Focuses on the social determinants of health and the ways in which our social context, including political, cultural, and economic circumstances, impact our health and shape our health behaviors.

- Identify / define social-environmental influences
- Investigate pathways of effect
- Devise ways to address social-environment

## Care Cascade RSA - Data from 2014

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Lippman et al, JAIDS 2016

# Addressing 90-90-90 through a social epi frame

#### 90-90-90- woes

- People aren't testing
- People not engaging in care / treatment
- Disparities in testing, treatment, viral suppression

#### Social epidemiology

- Identify / define socialenvironmental influences
- Investigate pathways of effect
- Devise ways to address socialenvironment

#### **Targets for change**

Create an enabling environment for people to engage in care. Address

- Stigma
- Gender norms

Shore-up community resources

 Shared Concerns/ Cohesion / Collective Efficacy to encourage HIV testing & tx in the community

# Collective Efficacy; Social Cohesion; Social Capital

- To tackle social problems, communities need some level of working trust and mutual expectation to intervene for shared interests.
- Social cohesion shared values & identity; sticktogetherness; ties to group/place; feeds social cooperation
- Pathways of influence:
  - Impacts health behaviors through diffusion and reinforcement of healthy normative behaviors – diffusion is facilitated in more 'cohesive' communities
  - Cohesive communities can provide an environment that enables and encourages people to enact healthy behaviors – both for themselves and for their peers/neighbors

## Social cohesion - 2 communities RSA

Cohesion Scale – shared trust and solidarity	NW (N=43 clusters)	MP (N=27 clusters)
Items	% agree	% agree
People in this community are willing to help their neighbors	47%	<b>68</b> %
This is a close knit community	38%	73.4%
People in this community can be trusted	24.2%	63.7%

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Grp Cohesion:  $1.00 \pm 0.18$ ;  $1.49 \pm 0.15$  (p<.01)





# Example: behaviors - two contexts

## Data from population-based surveys 18-49

Behaviors	North West (N=43 clusters; 1044 pts) N (Col. %)	Mpumalanga (N=27 clusters; 2057 pts) N (Col. %)	Chi square test p-value
Heavy drinking			
Men (N=401, 1004)	179 (44.6)	232 (23.1)	p<0.01
Women (N=643, 1053)	95 (14.8)	22 (2.1)	p<0.01
HIV testing in past y	ear (among those	not previously diag	(nosed)
Men (N=372, 767)	158 (42.5)	554 (72.2)	p<0.01
Women (N=555, 978)	344 (62.0)	819 (83.7)	p<0.01

# Group cohesion and behaviors

	<b>Men</b> POR (95% CI)	Women POR (95% CI)
Heavy drinking	· · · ·	
Between-group effects	N=1335	N=1695
Study: Mpumalanga relative to North West	0.15 (0.05, 0.43)*	0.06 (0.03, 0.15)*
Cohesion in North West	2.07 (0.83, 5.14)	1.31 (0.78, 2.20)
Cohesion in Mpumalanga	0.40 (0.25, 0.65)	0.32 (0.07, 1.49)
HIV testing past 12 months		
Between-group effects	N=1079	N=1532
Study: Mpumalanga relative to North West	2.44 (1.14, 5.25)	5.81 (3.35, 10.05)*
Cohesion in North West	1.46 (0.65, 3.30)	0.62 (0.42, 0.90)
Cohesion in Mpumalanga	<del>1.59 (1.10, 2.30)</del>	<del>1.86 (1.01, 3.40)</del>

# Implications - context and risk

- Health benefits when group cohesion is high.
- No health benefits where group cohesion is low.
- A minimum threshold or level of group cohesion required to yield positive health effects?
- Some basic level of cohesion (and likely other community contextual elements) may need to be present before benefits can be realized.

## SO: Can social cohesion be 'built'?



# One Man Can – Community Mobilization Program 2012-2014

Sonke Gender Justice's "One Man Can"

- Engaging men to question traditional norms of manhood & masculinity.
- Consider intersection of gender norms and HIV risk
- Personal action & encourage collective building of gender equity & HIV prevention

Cluster-randomized trial Intervention conducted in 11 villages with 11 control villages – within Agincourt HDSS .



love passionately stop aids end domestic violence break the cycle demand justice stop rape



(R01MH087118, Pettifor; R21MH090887, Lippman)





# OMC intervention activities aimed at increasing social cohesion

ACTIVITIES	Social cohesion
Establishing Community Action Teams (cadres of volunteers)	Create neighborhood volunteer structure – diffuse shared values/goals
Small group workshops	Foster a discussion group – shared goals, trust - Continued with future chat lists / contacts
Mini (2-3 hour) workshops	As above
Engaging CBOs/churches	Extend network messages for shared goals
Community Murals	Messaging towards common goals
Soccer tournaments	Activities with team – foster group
Community events/ forums/ feedback	Create larger dialogue in the community around shared goals
Photovoice workshops	Create common visual thread – building on shared experience



# Did we increase social cohesion?

Not at the community level (increased more in intervention villages – but not significantly so).

BUT - Cohesion scores were highly associated with increased exposure to OMC (intervention) activities

	Con	Control		Intervention	
	comm	communities		communities	
Social Cohesion	baseline	endline	baseline	endline	Mean difference p-value <sup>§</sup>
Mean	-0.02	0.11	-0.16	0.04	0.38
(sd)	(0.20)	(0.17)	(0.21)	(0.28)	

All survey data is weighted to account for sampling probabilities; <sup>§</sup> t-test examining difference in means over time (n=22 villages).

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# Did we increase HIV testing?

Structural equation model to assess pathways from intervention to HIV testing uptake.

Found CM intervention increased HIV testing through direct exposure (not indirect/diffusion)


### Conceptual Framework - CM for TasP

Social Barriers to Testing, Linkage, Retention

Lack of community awareness about benefits of testing & treatment

HIV-related stigma / fear of disclosure

Gender norms that discourage men from engaging in care

Lack of community support for testing and treatment

Fears around treatment side effects

Components of Community Mobilization

> Shared concern (HIV/TasP)

Community

consciousness

**Organizations/** 

networks

stigma / gender workshops

Leadership

Collective

activities

establish community action teams

community theater, outreach, discussions

engage community leadership

engage PLWHA, homebased care & clinic staff

Social cohesion

Improved Testing, Linkage, Retention Rates

Testing and treatment for HIV undesrtood as community issue / community benefit

Men engaged in HIV testing and care

Reduced stigma around testing & treatment

Improved testing, linkage, retention – more viral suppression

New HIV infections prevented

# Concluding thoughts

- Social environment / social resources impact health
- Changing social context should have impacts far beyond one health outcome in a community – can impact a host of health outcomes – room for synergy
- But we're still figuring out:
  - How to optimize programming
  - What other ingredients go into the mix
  - How long we need to make change (personal change to diffusion?)
  - Who to target with activities / involve
  - Reminder that we've come a long way!



### Acknowledgements: collaborators

#### All over:

- Audrey Pettifor & Suzanne Maman, UNC
- Kathleen Kahn, Xavier Gomez-Olive & Rhian Twine MRC/Wits
- Scott Barnhart & Jessica Grignon, UW / I-Tech
- Dean Peacock & Dumisani Rebombo, Sonke Gender Justice
- Hannah Leslie, Harvard

#### UCSF:

- Tor Neilands
- Starley Shade
- Teri Liegler
- Mi-suk Kang-Dufour

#### **Family:**

- Carlos (8 years)
- Diego (10 years)

### Acknowledgements: Funding

- North West Survey
  - CDC: Cooperative Agreement GH000324 to UW (Barnhart / Lippman)
  - UCSF-GIVI CFAR (Lippman / Liegler)
- Community Mobilization / Gender Norms program (2012-2014)
  - R01MH087118 (Pettifor)
  - R21MH090887 (Lippman)
- Community Mobilization for TasP (2015-2018)
  R01MH103198 (Lippman/Pettifor)

#### Using Behavioral Economics to Improve HIVrelated Behaviors



#### Sebastian Linnemayr, PhD

Senior Economist Professor, Pardee RAND Graduate School Co-lead, RAND HIV Interest Group



#### *Why Behavioral Economics?*



Policy Implications: Traditional vs. Behavioral Economics

- Traditional policies often assume a "rational actor":
  - People do what is best for them
  - If they show unhealthy behaviors information is missing or prices are wrong
- Limited policy options:
  - $\rightarrow$ Information provision
  - $\rightarrow$  'Paying' people to be healthy



A Simple Flashcard Test to Detect Concussions





Vegetarian Diet May Cut Colon Cancer Risk



John D. Arras, Medical Care Philosopher, Is Dead at 69 Liberian Leader Concedes Errors in Response to Ebola Ebola Outbrea Summer, U.N.

#### HEALTH

#### Study That Paid Patients to Take H.I.V. Drugs Fails

By DONALD G. McNEIL Jr. FEB. 24, 2015



- BE goes beyond this model, recognizes
  - our cognitive limitations (how we process statistics, for example)
  - our struggle with self-control

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- *BE goes beyond this model, recognizes* 
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  - our ungle with self-



#### Policy Levers for Behavioral Economics

#### economics

- **Behavioral economics** suggests that if we know a person's decision environment we can infer their behavior and influence it by:
  - Altering the decision environment
  - Designing incentives using decision-making errors ("biases") as entry points for interventions and policy

# *What does BE tell us about HIV as a decision-making environment?*

#### People tend to make good decisions if:

- The decision is simple
- Action and outcome clearly linked
- Good feedback
- Example: headache/aspirin

#### People tend to make good decisions if:

- The decision is simple
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- Good feedback
- Example: headache/aspirin

# Most chronic health behaviors (incl. HIV prevention and ART adherence):

- Long-term behavior change needed
- Costs now, benefits far in the future
- Low salience health threat
- Infrequent feedback

Linnemayr S. "HIV Prevention through the Lens of Behavioral Economics." JAIDS 2015, 68(4): e61-e63.

#### Key behavioral economics biases

#### HIV Prevention Through the Lens of Behavioral Economics

#### To the Editors:

A number of biomedical tools to prevent transmission of HIV are currently available including male and female condoms, pre-exposure prophylaxis (PrEP), microbicides, treatment as prevention (after the encouraging results

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which individuals are likely to make systematic decision-making errors or "biases" that in turn provide entry points for interventions. BE has shed new light on a range of health behaviors,<sup>5</sup> but to date, few published studies exist for HIVrelated behaviors, and most involve conditional cash transfers (payments in exchange for a certain behavior). These transfers are to a significant extent inspired by traditional (neoclassical) economics and have been described elsewhere,<sup>6</sup> This letter instead discusses 3 BE biases that likely contribute to suboptimal prevention behaviors and suggests potential interventions to address them.

A key BE bias is *salience*, that is, the tendency for people to act on information that first comes to mind rather than making use of all available

www.jaids.com | e61

#### Salience

#### Present bias

#### Affect

Supported by the National Institutes of Health under grant number R34MH096609. The authors have no conflicts of interest to disclose.

Applications

#### **1. BE 'light': supporting other interventions:**

- Increasing the effectiveness of information provision & messaging
- Improving recruitment
- Increasing retention

#### **2. True BE-based interventions:**

- Incentive provision
- Nudging
- Changing default options
- Etc.

# *Empirical evidence on the prevalence of BE biases and their impact on ART adherence*



#### Rewarding Adherence Program (RAP) Kampala, Uganda





# Prize value: \$2 USD per person/year



#### Small, non-monetary incentives successfully improve ART adherence



**Linnemayr S,** Stecher C, Mukasa B. "Lottery incentives to improve adherence to antiretroviral (ARV) drugs: evidence from the first nine months of a small randomized controlled trial in Uganda". *AIDS* 2017, 31(5):719-726.

#### SITA Study - Peer competition as nonmonetary incentive:

- Weekly message, sent to 170 adolescents receiving HIV care in Uganda
- If successful, scalable and almost zero running costs

"Congratulations, you took 70% of your meds this week. Your friends took 85%..."





- Behavioral economics is different from traditional economics in that it explicitly recognizes we all make mistakes
- These mistakes ("biases") are predictable once we know the decision environment
- For chronic health behaviors, key challenges are
  - Need for daily action with delayed benefits  $\rightarrow$  present bias
  - Slipping of health problem from mental priority list  $\rightarrow$  low salience
- These same biases are entry points for interventions Salience: mobile technologies / reminders? Present bias: incentives?

- SBSRN for invitation
- NIH for funding most of the research this presentation is based on
- Study participants and Staff at Mildmay, IDI, and TASO clinics and Bienestar Human Services where the research was implemented

#### Thank you!

#### slinnema@rand.org

#### Appendix: Insights from BE for design of incentives

	Traditional Economics	Behavioral Economics
Dealing with preferences	Overrides preferences	Supports individual's preferences Nudges towards those of the rational, 'cool' self 'Angel' (Dec 31) vs. Devil (Jan 1)
Type of incentive	TUL CALLED STATES OF AMERICA TUL CALLED STATES OF AMERICA 1 2 0 DUST TUL CALLED TUL CA	Money (Can backfire!) In-kind Chance to be kind (self-identity) Social prestige ("Employee of the month") 
Allocation mechanism	Fixed (Quid pro quo)	Contingent Unconditional Fixed Variable (Lotteries, raffles,)
	Does not matter	As a loss avoided (loss aversion) As a separate payment (salience)

Improving Chronic Health Behaviors, with an Application to Adherence to Antiretrovirals". *JAIDS* 2016,

# Examining social networks in context:

THE IMPORTANCE OF CHOSEN FAMILIES AND KINSHIP IN HIV PREVENTION AND CARE WITH SEXUAL AND ETHNIC MINORITY (SEM) YOUTH

Emily A. Arnold, Ph.D., Center for AIDS Prevention Studies, University of California San Francisco

# What does ethnography contribute to research on HIV prevention and care?

Ethnographers can learn not just what people tell us they do, but what they actually do.

Ethnographic fieldwork has documented the salience of chosen family systems for sexual, gender and ethnic minority communities for decades, where 'kin' both provide and receive various social resources, including those related to HIV.

# Kin can be constructed from a variety of social relationships

- Extended Kin (Stack, 1974): Friends become kin to overcome poverty
- Chosen Kin (Weston, 1991; Hawkeswood, 1996): Gay and Lesbian individuals become kin
- House Ball Communities (Arnold and Bailey, 2009): SEM youth create forms of kinship (houses) that compete in balls



# Kin can be conceptualized as social networks and analyzed

Individual connections govern:

- Flows of Information
- Access to Material Resources
- Social norms
- Health behaviors
- Disease Transmission

(Lin, 2001, Valente, 2010, Christakis and Fowler, 2011)



# Social support flows through kin networks and impacts HIV-related health behavior



# Houses and Gay Families are Kin for SEM youth



# Chosen Kin Networks and HIV

Social support and social norms around risk, testing, care, and treatment circulate within the houses and gay family networks of SEM youth

- Social Support is gendered, with "mothers" and "fathers" often acting as sources of different forms of support
- Support is reciprocal, especially among "siblings"
- Community events, such as prevention balls, convene family networks and reinforce norms around HIV prevention, testing and care

Kevin Blahnik and Mario B. Present

### The Pride Mini Ball

Women Body Runway Butch Streetwear Realness Face BQID Runway Realness Face Face

Face Realness Runway Body Models v. Luscious Saturday, September 3, 2011 10pm - 2am 1738 Telegraph Blvd., Oakland CA 94612 \$15 at the Door Questions Call Kevin Blahnik 5104354516 BQ

Sex Siren Realness Pretty v. Thug v. Schoolboy v. Executive RWT Part 1 and Part 2 Jeans and a T-shirt No Hats Vogue Fem Soft'n'Cunt v. Dramatics BQ European Runway Tall v. Small v. Big All American Runway

Minigrand OTA Performance Thunderdome \$10 pot "Two Men Enter, One Man Leaves" Grand Prize OTA Runway Winners Of The Runway Categories Must Battle For The Cash All Categories are bring in Black and White

# Chosen kin provide essential forms of support

I think there is definitely a lot of things that are necessary to my well-being that happen in the house... We definitely encourage each other...I've actually had these conversations with people, like, 'Let's go get tested. Let's go tomorrow. It doesn't take long at all.' (House of Revion member)

[My gay father] *always instilled morals and values and good advice in me as if he was really my father....When we do talk or text it's always encouraging things like, 'What's going on? Are you working? If you're not working are you looking? Do you need help with your resume?' And when I told him I was applying for school he was like, 'Do you have any fees that you need to be covered?'* (Gay Family member)

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What structural characteristics and types of support are associated with better HIV-related health outcomes for SEM youth?





#### $\mathcal{O}$

# We examined...

• Size

- Density (who knows who in the network)
- Homophily (how alike or different our participants were from the people in their networks)
- Provision of specific types of social support (instrumental, informational, emotional and HIVspecific)



# HIV-specific Support and Homophily Matter

Participants with a <u>higher percentage of alters who were supportive of HIV testing</u> were more likely to have tested in the past 6 months (p=.02) and less likely to have had UAI in past 3 months (p=.003).

HIV testing in past 6 months was associated with <u>social support for condom use, instrumental</u> <u>social support</u>, and age.

UAI in the past 3 months was associated with <u>homophily (based on sexual identity) in the network,</u> <u>social support for condom use</u>, and HIV status.

(Arnold, Sterrett-Hong, Jonas, Pollack, 2016)
## How do we use these findings to develop and refine intervention approaches?

# We Are Family: Using kinship networks to reach the 90-90-90 for SEM youth

Network Structure	Cognitive Social Capital	Intervention Activities and Delivery
Density	Informational support HIV-Specific support Instrumental support Social Norms	Identify houses and gay families to work with, especially 'parents' who provide HIV-specific supportHIV-specific support should promote testing, linkage to care, engagement in care and treatment adherenceAddress HIV-related stigma and rehearse challenging norms that promote HIV-related stigma
Homophily	Emotional support Instrumental support Informational support HIV-Specific support Social Norms	Mimic house meetings or gay family gatherings, capitalizing on homophily within the networks <u>Acknowledge SGEM diversity, and develop trans-specific content and resources</u> <u>Ensure that visuals affiliated with the project are representative of participants, encourage youth to</u> <u>provide content for online narratives</u>
Size	Instrumental Support Informational Support HIV-Specific Support Social Norms	Convene Community-Level events (balls) to increase network size, shift norms, and underscore strength of family ties    Mhealth and online approaches can be used to increase network size, provide informational support, and promote healthy social norms across the networks   Local HIV-specific resources can be reviewed by members of the community, a form of HIV-specific support



#### WIF WE ARE FAMILY

#### **REAL STORIES** FROM THE COMMUNITY



#### **KNOWLEDGE UP** GET THE FACTS

It is best to wait as long as possible before you start taking HIV medications.





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Think that today's HIV medications affect how you look. The facts >

### Thank you

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I gratefully acknowledge funding from NIMH (K01MH077489) and the California HIV/AIDS Research Program (HD15-SF-060) that has supported this work, as well as the tremendous contributions of my research team and our participants.