The PATHways Program at the Vanderbilt Comprehensive Care Clinic: Successfully Reaching and Engaging the "Last Ten Percent"

HIV Symposium

November 2, 2018

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Acknowledgements

- Stephen P. Raffanti, MD, MPH
- David M. Aronoff, MD
- PATHways Team:

  Karie Holldorf, MSN, RN
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  Kira Zemanick, RN
  Judy Stilke, RN
  Raven O'Rourke, LCSW*

- The entire staff of the Vanderbilt Comprehensive Care Clinic (VCCC)
- Tennessee Center For AIDS Research (CFAR)
- Ryan White, Part B
- Southeast AIDS Education and Training Center (SEAETC)

Disclosures

- No financial disclosures.

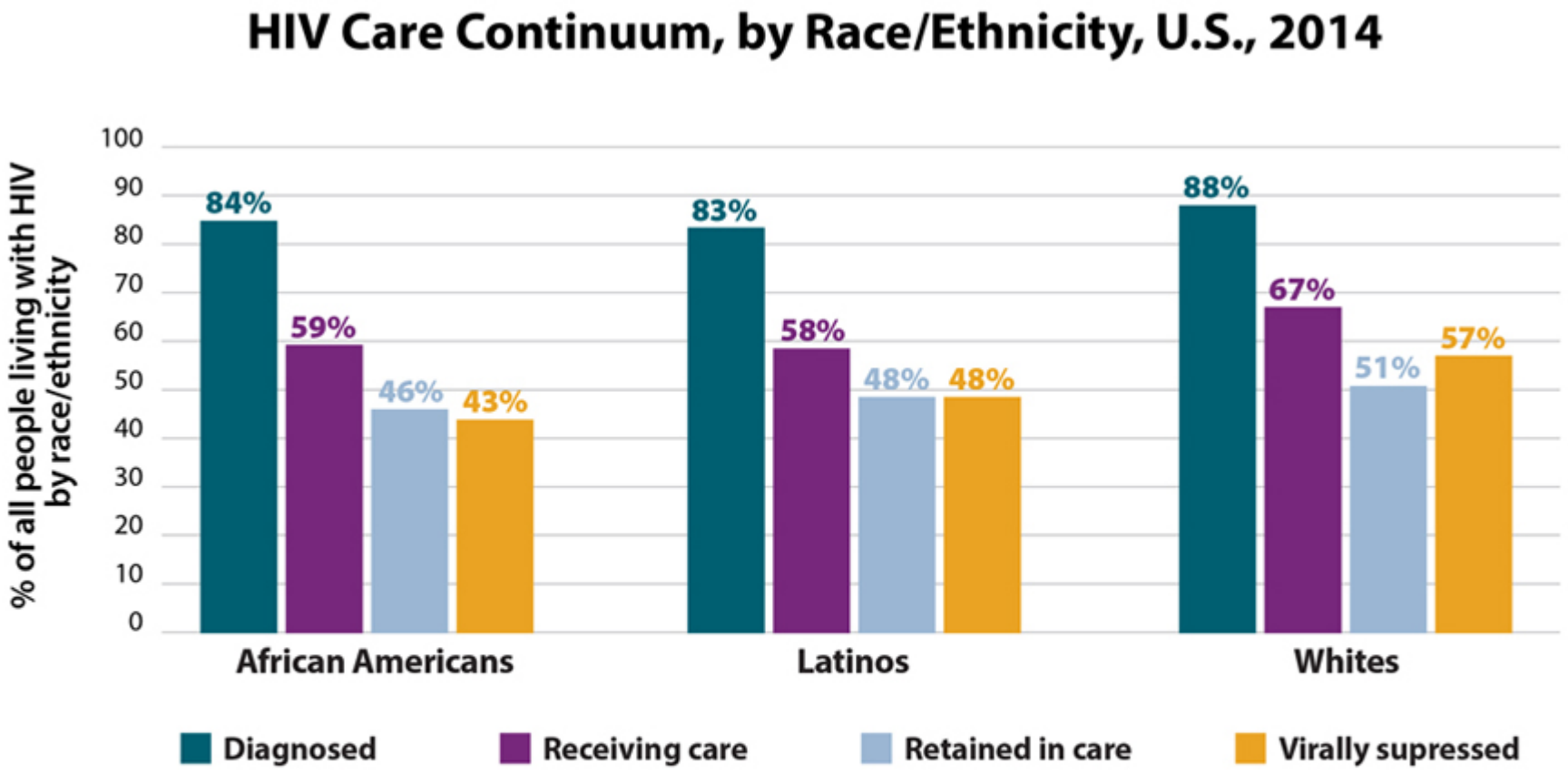
- This talk will, of necessity, include political statements. The transmission and course of HIV are both directly impacted by social forces, and those cannot be examined without discussing the tool that we have developed to manage social power, which is politics.

  I have no desire to offend any participants.

Outline

- Scope of the Problem: Why are Some People Living With HIV (PLWH) Still Unengaged in HIV Care?
- PATHways Model of Care
- Multi-dimensional Patient Strengths Phenotype (MDPSP)
- Future Plans – PATHways 2.0

The Usual Suspects: The Slide Shown at Every HIV Talk in the South



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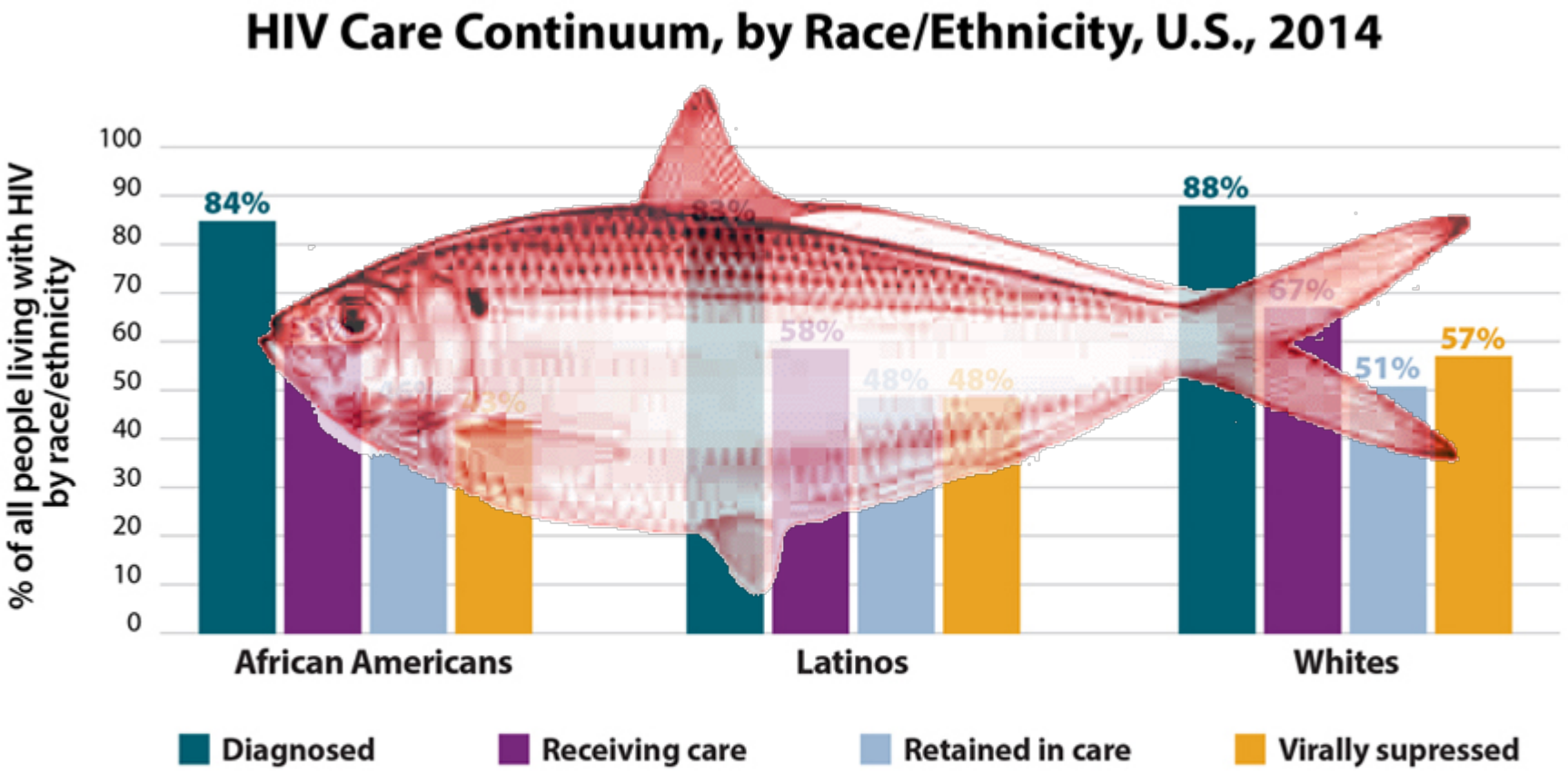
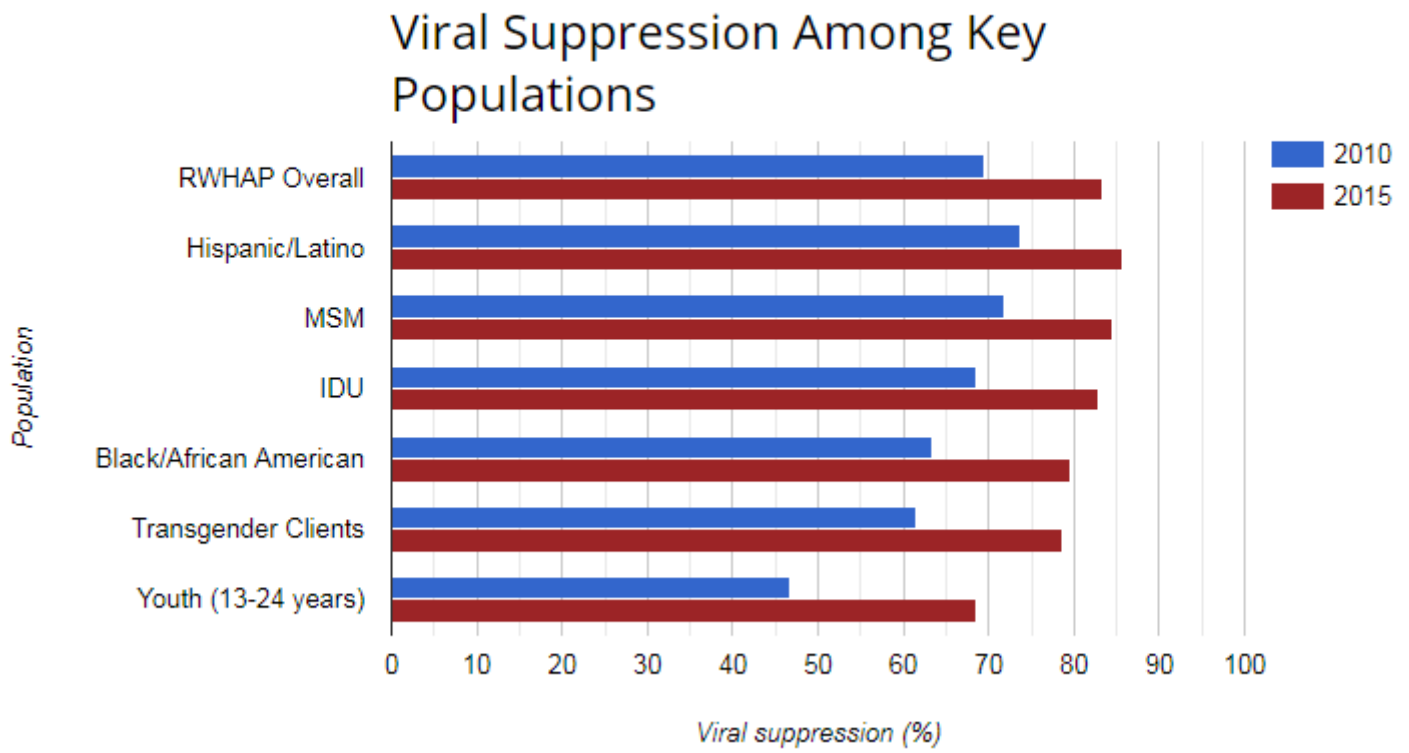


IF You Engage in HIV Care, You Will Do Well -

Viral Suppression among Key Populations Served by the Ryan White HIV/AIDS Program, 2010-2015 – United States



https://hab.hrsa.gov/stateprofiles2015/#/

Existing Solutions

- VCCC has HIV viral suppression rate of approximately 88%, driven by the wide range of resources available in our clinic

- There are published interventions to individually address the barriers to care faced by PLWH in the Southern US

- Challenges:
  - Very difficult to integrate any intervention into a busy HIV clinic workflow
  - No standardized data collection to facilitate more effective interventions
  - Nothing targeting patient and provider together

Why Keep Using the Same Model?

- We know we can get good results once people engage with Ryan White services. Why can't we improve rates of engagement/retention/ viral suppression in the remainder of PLWH?

- Does skin color, in and of itself, really explain the current rates of engagement in care?
  - Skin color is a proxy for a host of issues we are unable to discuss in our society

- What aren't we seeing???

Painful Truths

- By and large, we are all working within the same models of care that we have used for at least the last decade
- This model works *in many cases*, as evidenced by the rates of HIV viral suppression for those retained in Ryan White Clinics
- HOWEVER, unengaged PLWH are not holding out until we develop ART with even fewer side effects and lower pill burdens
- Nor are they resigned to living with unsuppressed HIV because they know that they can’t fight a virus that is more aggressive in people of a certain skin color or income

One Key: Acknowledge the Environment

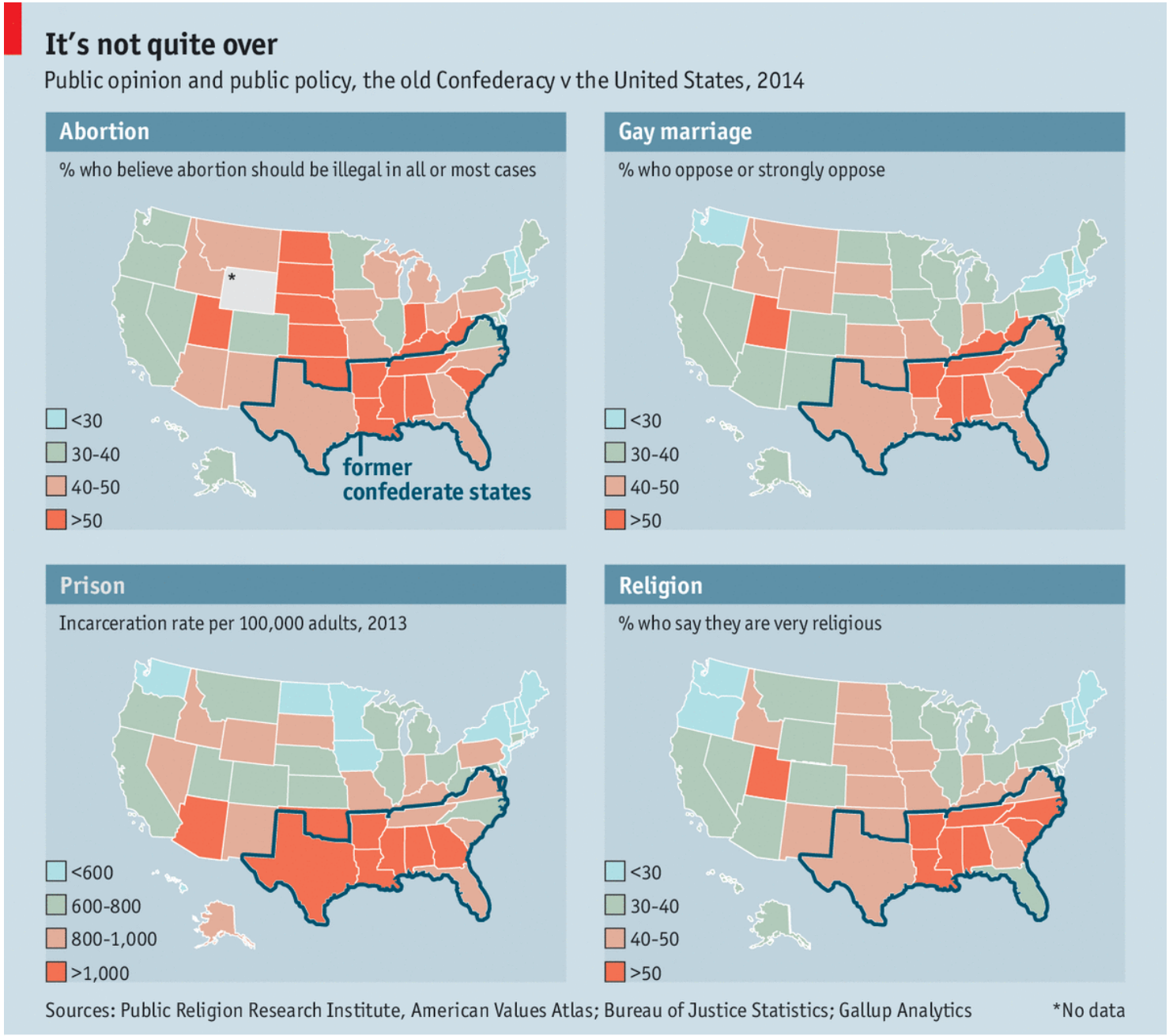
Homeostasis – How one is doing "from the skin in"

- Original conception of health
- If vital signs are normal, then the patient is doing well

Allostatic Load – newer model measures the impact of environment on health

Marginalizing Social Attitudes in the Southern US

Survival is Threatened in a Toxic Environment



https://www.economist.com/united-states/2015/04/04/the-present-past

Adverse Childhood Events (ACE): The Impact of Environment on Human Health

Findings from CDC-Kaiser Community Sample (N=17,337):

"Persons who had experienced four or more categories of childhood exposure, compared with those who had experienced none, had a 4- to 12-fold increased health risks for alcoholism, drug abuse, depression, and suicide attempt; a 2- to 4-fold increase in smoking, poor self-rated health, > 50 sexual intercourse partners, and sexually-transmitted disease; and a 1.4- to 1.6 fold increase in physical inactivity and severe obesity."

Felitti, VJ, et. al. (1998) Relationship of Childhood Abuse and Household Dysfunction to Many of the Leading Causes of Death in Adults, *Am J Prev Med*, (14), 4, 245-58.

CDC-Kaiser Findings vs. VCCC: PATHways (48) and Newly-engaged (83) Patients

Number of Adverse Childhood Experiences (ACE Score)	Kaiser-CDC N=17,337	VCCC Newly Engaged N=83	VCCC PATHways N=48
0	36.10%	22.9%*	6.3% #
1	26%	38.6%*	8.3% ##
2	15.90%	9.60%	6.30%
3	9.50%	15.70%	16.70%
4 or more	12.50%	13.30%	62.5% ##

Kaiser vs Newly-engaged: * $p < 0.05$; ** $p < 0.001$

Newly-engaged vs PATHways: # $p < 0.05$; ## $p < 0.001$

CDC-Kaiser Findings vs. VCCC: PATHways (48) and Newly-engaged (83) Patients

ACE Category	Kaiser-CDC N=17,337	VCCC Newly Eng N=83	VCCC PATHways N=48
ABUSE			
Emotional Abuse	10.60%	15.7%	50% ##
Physical Abuse	28.30%	10.8%**	35.4% ##
Sexual Abuse	20.70%	9.6%*	56.3% ##
HOUSEHOLD CHALLENGES			
Mother Treated Violently	12.70%	9.6%	20.5%
Household Substance Abuse	26.90%	22.9%	52.1% ##
Household Mental Illness	19.40%	19.3%	43.8% #
Parental Separation or Divorce	23.30%	59.0%**	83.3% #
Incarcerated Family Member	4.70%	10.8%*	47.9% ##
NEGLECT (subset of 8,629 only)			
Emotional Neglect	14.80%	22.9%*	56.3% ##
Physical Neglect	9.90%	3.6*%	33.3% ##

Kaiser vs Newly-engaged: * $p < 0.05$; ** $p < 0.001$

Newly-engaged vs PATHways: # $p < 0.05$; ## $p < 0.001$

Self-Isolation as a Coping Strategy

To go out and meet people is " . . . too much effort, too much risk. Yeah, I, I don't know so much about the younger set of people, but in my particular group you are afraid to tell anybody and so yeah you are kind of isolated, kind of set you in a little group by yourself" *(46 year old white male).*

"I don't have any friends. I got a girlfriend I talk to on the phone . . . We just talk on the phone. Um, I stay in the house, I stay isolated. I'm very active in my church . . . but other than that, I don't go anywhere, I stay isolated and it's not good" *(42 year old African-American female).*

"I was there watching a film and this other guy that I knew, just not well, but he kind of wanted to get outta there and take off, you know? So I told him, he actually got up and walked away and never came back, never said a word, just got up and walked out the front door. So that was actually my first rejection if you want to call it that*"(44 year old white male).*

"Yeah, it's just like, it's like a curse. I mean because of everything I've been through with the way people have treated me and when people don't treat you right or people disown your friendship and you feel like you beat yourself up over it . . . The longer you're infected, the harder it is on a person . . . You know, you just, after a while, you start beating yourself up especially when you get sick" *(34 year old African-American female).*

Audet, CM, McGowan CC, Wallston, KA, Kipp, AM (2013). Relationship between HIV Stigma and Self-Isolation among People Living with HIV in Tennessee. *PLOS ONE*, (8), 8: e69564. doi: 10.1371/journal.pone.0069564

A New Paradigm of Care

- A new approach to care specifically designed to reach marginalized PLWH
- Nursing-led, interdisciplinary, individualized, intensive care for patients failing to manage their HIV and health secondary to burdens beyond their ability to control, such as CSA, HIV stigma, substance abuse
- Strengths-based, data-driven via use of the new Multi-Dimensional Patient Strengths Phenotype Screening Instrument (MDPSP)
- Long-term care, as long as required, in a patient-focused, intentional community

Features of the Program

- Pre- and post-clinic **interdisciplinary huddles** ensure that team is aligned re: patient progress, concerns, updates since last visit, goals for today's visit
- **Patients** are **actively engaged** in designing their own Plans of Care
- Strong **(daily) communication** with community **Ancillary Service Organizations** (ASOs)
- Ability to **meet** patients **in the community**
- Direct **phone/text access** to Program RN **personalizes clinic experience**
- **Hospital presence** facilitates smoother discharges and encourages connection to Clinic

The PATHways Phenotype: why a new patient screening tool?

- We need tools that capture the multi-dimensional nature of structural marginalization in the lives of our patients
  - Most assessments are one- vs multi-dimensional

- We need tools that can engage our patients in their own care

- We need tools that fit into the workflow of always busy, always understaffed HIV clinics

Novel Features of the PATHways Phenotype

- Easy to administer, estimate 20 mins. to complete Part A and 20 mins. to complete Part B on iPad
  - Most discrete data collection mode possible
  - Secure, data flows directly into REDCap

- Summary Interpretive Overlay (SIO)
  - Easy for patients and providers to quickly grasp the findings from a multidimensional set of screening tools

- Patients Actively Engaged in Developing and Implementing Plan Of Care
  - Phenotype provides a strengths-based roadmap to improved self-efficacy, leading to improved ART adherence

Summary Interpretive Overlay (SIO)

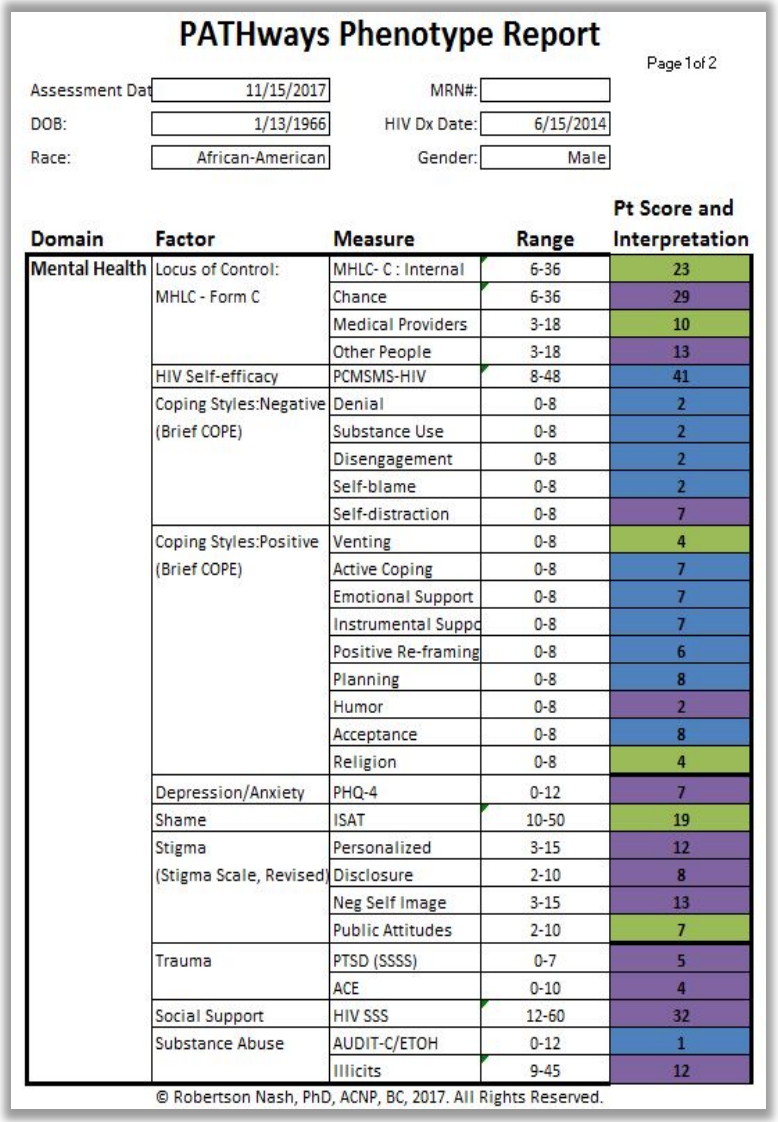
- Every instrument has independent scoring methodology; no interdependence of scores
- SIO assigns score to one of three ranges:

Scoring Key	Recommendation
PURPLE	Risk: This area should be further assessed and addressed to minimize risk of failing HIV care
GREEN	Baseline: Patient has minimal level of functionality in this area; further assessment recommended
BLUE	Goal: Patient at goal in this area; may represent opportunities to build on patient strengths

Examples of the SIO

Domain	Factor	Measure	Range	Risk	Baseline	Goal
Mental Health	Depression/ Anxiety	PHQ-4	**0-12**	**6-12**	**3-5**	0-2
	Trauma	ACE	**0-10**	**4-10**	**3**	0-2
Clinical Care	Health Insurance	Y/N		**N**	**N**	Y
Social Environment	Intimate Partner Violence	HITS	**4-20**	**10-20**	**7-9**	4-6
Education	Highest Grade			<12	<12	12

PATHways Phenotype, Complete



PATHways Phenotype Report

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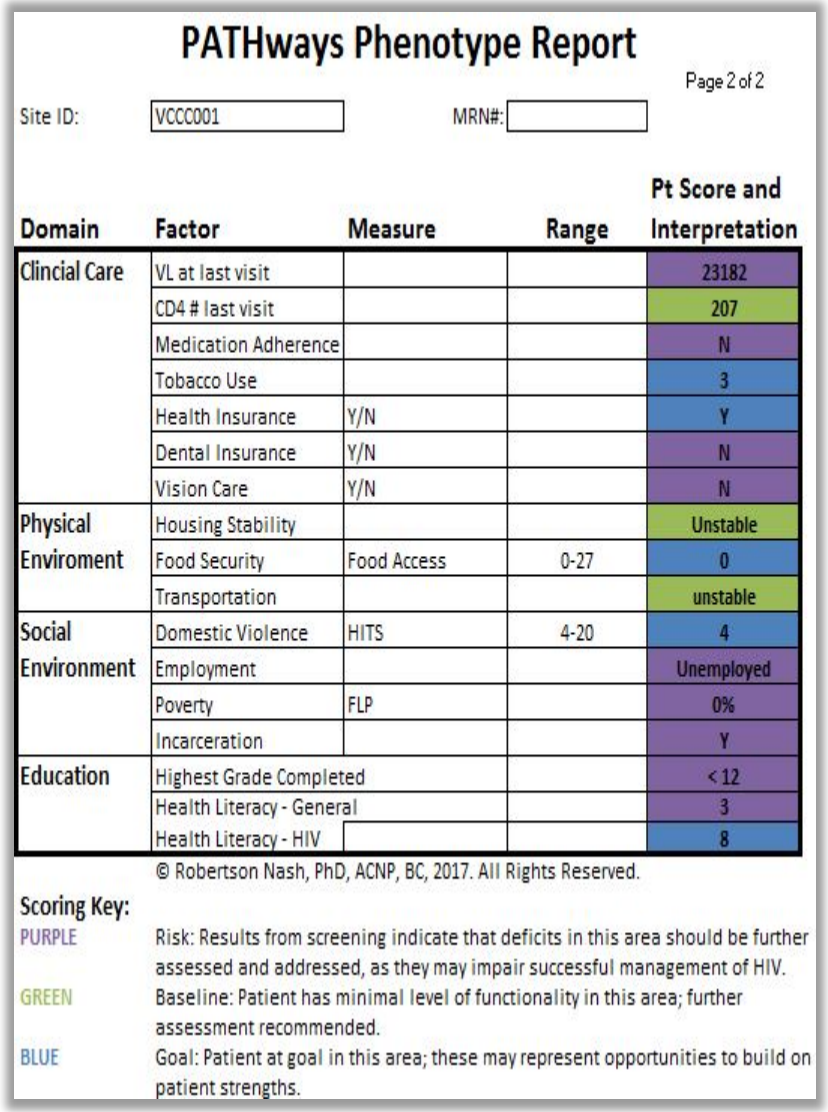
Assessment Dat: 11/15/2017 MRN#:
DOB: 1/13/1966 HIV Dx Date: 6/15/2014
Race: African-American Gender: Male

Domain	Factor	Measure	Range	Pt Score and Interpretation
Mental Health	Locus of Control: MHLC - Form C	MHLC- C : Internal	6-36	23
		Chance	6-36	29
		Medical Providers	3-18	10
		Other People	3-18	13
	HIV Self-efficacy	PCMSMS-HIV	8-48	41
	Coping Styles:Negative (Brief COPE)	Denial	0-8	2
		Substance Use	0-8	2
		Disengagement	0-8	2
		Self-blame	0-8	2
		Self-distraction	0-8	7
	Coping Styles:Positive (Brief COPE)	Venting	0-8	4
		Active Coping	0-8	7
		Emotional Support	0-8	7
		Instrumental Suppo	0-8	7
		Positive Re-framing	0-8	6
		Planning	0-8	8
		Humor	0-8	2
		Acceptance	0-8	8
		Religion	0-8	4
	Depression/Anxiety	PHQ-4	0-12	7
	Shame	ISAT	10-50	19
	Stigma (Stigma Scale, Revised)	Personalized	3-15	12
		Disclosure	2-10	8
		Neg Self Image	3-15	13
		Public Attitudes	2-10	7
	Trauma	PTSD (SSSS)	0-7	5
		ACE	0-10	4
	Social Support	HIV SSS	12-60	32
	Substance Abuse	AUDIT-C/ETOH	0-12	1
		Illicits	9-45	12



PATHways Phenotype Report

Page 2 of 2

Site ID: VCCC001 MRN#:

Domain	Factor	Measure	Range	Pt Score and Interpretation
Clincial Care	VL at last visit			23182
	CD4 # last visit			207
	Medication Adherence			N
	Tobacco Use			3
	Health Insurance	Y/N		Y
	Dental Insurance	Y/N		N
	Vision Care	Y/N		N
Physical Enviroment	Housing Stability			Unstable
	Food Security	Food Access	0-27	0
	Transportation			unstable
Social Environment	Domestic Violence	HITS	4-20	4
	Employment			Unemployed
	Poverty	FLP		0%
	Incarceration			Y
Education	Highest Grade Completed			< 12
	Health Literacy - General			3
	Health Literacy - HIV			8

Scoring Key:

PURPLE — Risk: Results from screening indicate that deficits in this area should be further assessed and addressed, as they may impair successful management of HIV.

GREEN — Baseline: Patient has minimal level of functionality in this area; further assessment recommended.

BLUE — Goal: Patient at goal in this area; these may represent opportunities to build on patient strengths.

PATHways Phenotype, Version A

PATHways Phenotype, Initial/New Diagnosis

Assessment Date:	3/28/2018	MRN#:	46340355
DOB:	6/21/1991	HIV Dx Date:	2/23/2018
Race:	Caucasian	Gender:	Male

Domain	Factor	Measure	Range	Pt Score and Interpretation
Mental Health	General Self-efficacy	GSE	10-40	29
	Impulsiveness	BIS-8	8-32	16
	Depression/Anxiety	PHQ-4	0-12	6
	Trauma History	ACE	0-10	5
	Alcohol Use	AUDIT-C	0-12	2
	Illicit Use	POST	9-45	18
Clincial Care	VL at last visit	EMR	3/28/2018	25153
	CD4 # last visit	EMR	3/28/2018	339
	Tobacco Use	POST		Y
	Health Insurance	Y/N		Y
Physical Environment	Housing Stability			lives w/family
	Transportation			unstable
Social Environment	Employment		FT/PT/U/D	Unemployed
	Poverty	% FLP (mon income)		0%
Education	Highest Grade Completed			12

Scoring Key:	
PURPLE	Risk: This area should be further assessed and addressed to minimize risk of patient failing HIV care.
GREEN	Baseline: Patient has minimal level of functionality in this area; further assessment recommended.
BLUE	Goal: Patient at goal in this area; these may represent opportunities to build on patient strengths

Recommendations:	
Mental Health:	Refer for care, offer substance abuse resources
Clinical Care:	Monitor medication adherence, offer smoking cessation referral
Physical/Social Environment:	Encourage patient to connect with community service organizations re: housing, transportation, and employment
Education:	Adjust teaching to accommodate patient's education/health literacy level

Provider Review: _____

Patient Barriers to Care Assessed by MDPSP

	All (N=179)		Newly Engaged (n=83)		PATHways (n=53)		New Engaged vs PATHways
Single Barriers	**Count**	**Pct**	**Count**	**Pct**	**Count**	**Pct**	***p***
Trauma	45	*25%*	12	*14%*	28	*53%*	< 0.001
Addiction	93	*52%*	46	*55%*	35	*66%*	0.310
Poverty	60	*34%*	23	*28%*	27	*51%*	0.027
Transportation	39	*22%*	7	*8%*	29	*55%*	< 0.001
Housing	37	*21%*	6	*7%*	26	*49%*	< 0.001
Education	19	*11%*	4	*5%*	12	*23%*	0.005
None	29	*16%*	7	*8%*	4	*8%*	1.00
Multiple Barriers							
Trauma + Addiction	35	*20%*	10	*12%*	23	*43%*	< 0.001
Trauma + Addiction + Poverty	23	*13%*	4	*5%*	17	*32%*	< 0.001

MDPSP Barriers to Care by Race/Gender

	All by Race		All by Gender		Males (n=121)		Females (n=29)	
	Non-White	White	Male	Female	Non-White	White	Non-White	White
Individual Barriers	**88**	**62**	**121**	**29**	**71**	**50**	**17**	**12**
Trauma	33%*	16%	24%	34%	30%	16%	47%	17%
Addiction	57%**	26%	41%	55%	59%	16%	47%	67%
Poverty	43.%*	26%	36%	38%	45%	22%	35%	42%
Transportation	26%	15%	17%	38%*	21%	12%	47%	25%
Housing	26%	16%	18%	38%*	20%	16%	53%*	17%
Education	17%	15%	12%	31.%*	13%	12%	35%	25%
No Barriers to Care	22%	16%	21%	14%	23%	18%	18%	8%
Multiple Barriers								
Trauma + Addiction	25%	21%	23%	24%	24%	22%	29%	17%
Trauma + Addiction + Poverty	16%	13%	16%	10%	15%	16%	18%	0%

* $p < 0.05$; ** $p < 0.001$

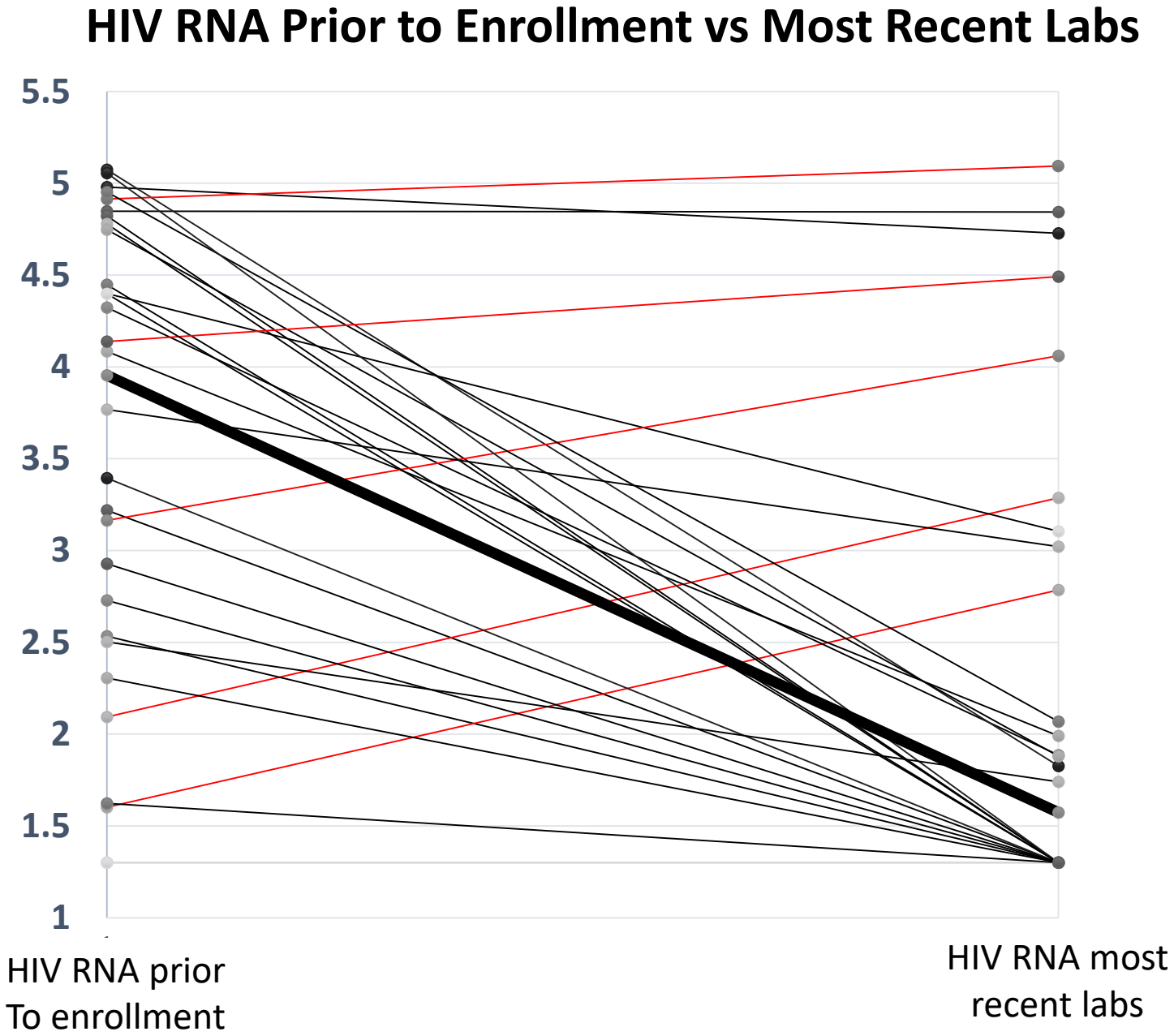
Observations from our Program

- People who engage in the program don’t want to return to regular clinical care
- We have inverted the no-show and cancellation rates in people that are in our program
  - People who used to be no-shows now call us and apologize if they need to re-schedule a meeting
- We have had very positive results providing pharmacotherapy plus behavioral health care to address anxiety and depression
  - Anxiety is a significant problem in this population
  - Easily addressed, immediate relief

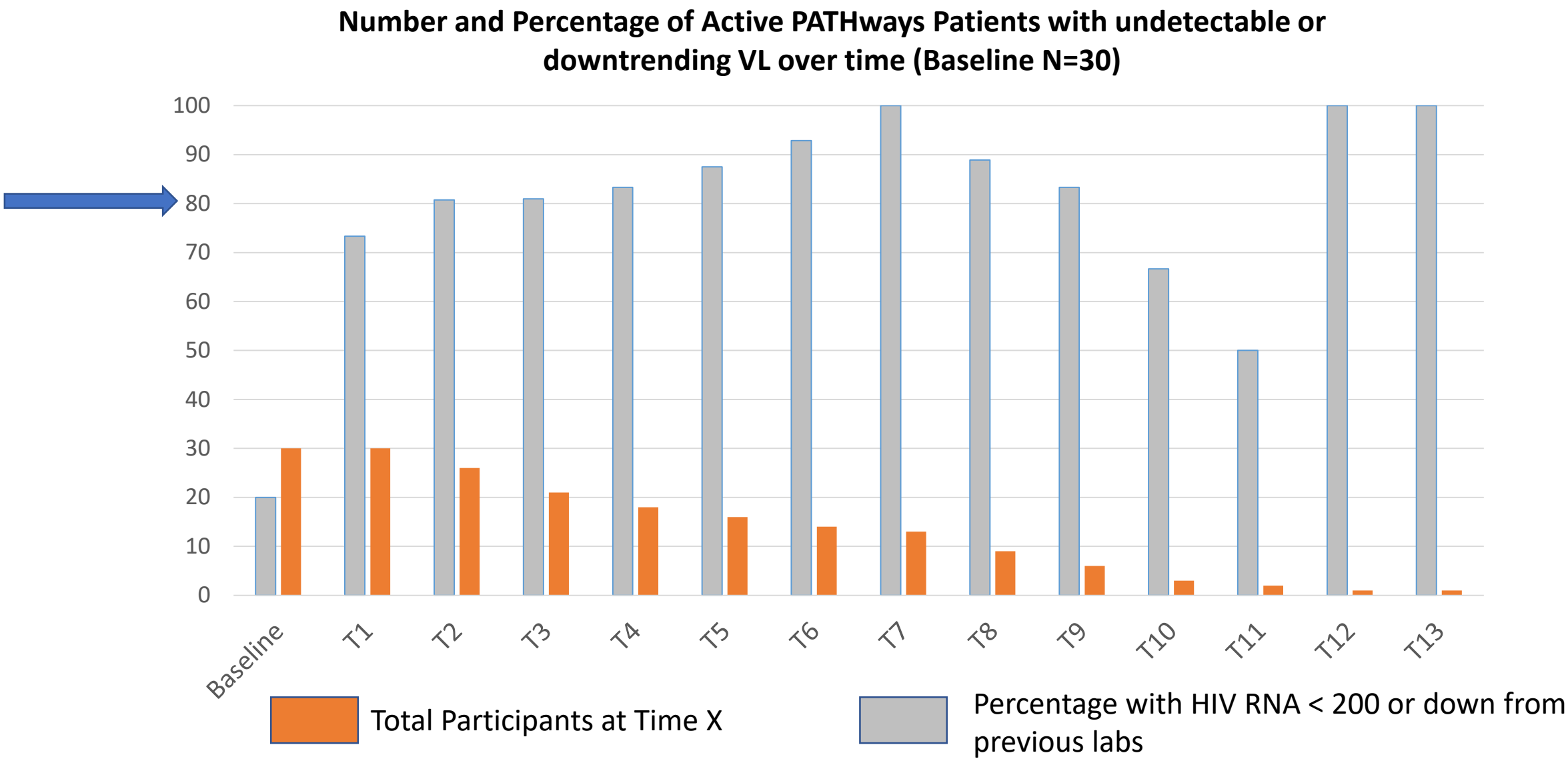
Outcome 1: HIV VL Suppression

Active PATHways Patients (30)

Dark Line = Median Change



Outcome 2: VL Suppression over time



PATHways 2.0 – Expanding Beyond the VCCC

- Our program has been intentionally developed with a **focus on smaller HIV clinics**. We feel that any clinic with at least **one interested provider** and **one Social Worker** should be able to **successfully implement** the program

- **MDPSP** will eventually be available as a tool that any HIV clinic can access for their own uses

- All **psychoeducation materials** will be **available via web** for downloading and use as needed

- We also envision working closely with the SEAETC to **support and grow a community of HIV clinics** using our approach care

PATHways 2.0 – Expanding Beyond the VCCC

- Targeted Psychoeducation Learning Materials, developed from and supporting MDPSP Domains and Factors of Care
  - Available via SEAETC for sites without behavioral health support
  - Designed for interactive learning with patient and “coach”
    - Wide range of clinic staff can be “coach”
    - **NOT** designed to replace therapy or psychiatric care
    - **GOAL** is to introduce patients to concepts that can help them better understand themselves, hopefully leading to greater self-worth then greater self-efficacy
- Trauma content in pilot phase, 6 other modules in development

PATHways 2.0 – Expanding Beyond the VCCC

- Expansion of instrumentation into Spanish
  - Validated Spanish versions available for all Behavioral Health instrumentation in Part A of the MDPSP
    - SEATEC has facilitated Spanish translation of consent form
    - Working with SEATEC re: Spanish translation of Housing and Transportation Surveys
  - Reviewing resources for behavioral health and psychoeducation teaching via translator

Publications

Submitted:

Towards a New Framework for Conceptualizing Patients Failing HIV Therapy: Addressing Trauma with Practice - Based Evidence and Parsimonious Theory

Nash, R, O'Rourke, R, Woodward, BO

In review, *Journal of the Association of Nurses in AIDS Care*

In Preparation:

Multi-Dimensional Patient Strengths Phenotype: Methods Paper

Nash, R, O'Rourke, R, Campbell, K, Woodward, BO

MDPSP Findings: Manuscripts to follow

Questions?