ACTHIV® ChangeMakers: Integrating Leadership Development and Implementation Science to Drive Local HIV Care Improvement

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BACKGROUND

The ACTHIV® ChangeMakers program was launched to build leadership capacity among HIV clinicians and support participants in driving positive change within their organizations and communities. The program began as a pilot in 2022 with a small group of HIV clinicians and has grown each year. Over four years, the program has expanded beyond foundational leadership skill-building to integrate implementation science as a practical toolkit for translating evidence into routine practice. While leadership is recognized as a core implementation determinant across multiple implementation science frameworks, ACTHIV® ChangeMakers also emphasizes the role of informal leadership as a catalyst for change in real-world HIV care settings.

METHODS

We describe the program's longitudinal evolution and summarize outputs from the most recent ACTHIV® ChangeMakers cohort. The curriculum continued to strengthen core leadership competencies (e.g., stakeholder engagement, communication, team-based change, and adaptive problem-solving) while increasingly emphasizing implementation science concepts (e.g., identifying barriers and facilitators, selecting strategies, testing changes, and planning for sustainment). Participants worked on action-learning projects designed to demonstrate leadership behaviors and apply implementation science principles to improve care delivery in their local contexts.

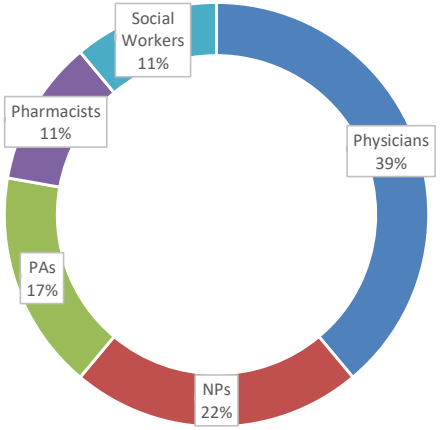
Action Learning Project: Allows participants to demonstrate their commitment to personal leadership and growth contextualized around the management of patients living with HIV.

Adaptive Leadership: A practical leadership framework that emphasizes collaborative problem-solving, continuous learning, and flexibility. *Practice of Adaptive Leadership: Tools and Tactics for Changing Your Organization and the World* by Ronald A. Heifetz, Marty Linsky, and Alexander Grashow (Harvard Business Press, 2009)

Implementation Science: The study of methods to promote the adoption and integration of evidence-based practices, interventions, and policies into clinical practice. Implementation science seeks to systematically close the gap between what clinicians know vs. what clinicians do (often referred to as the know-do gap).

RESULTS

The most recent cohort (2025-2026) included 18 interprofessional clinicians: 7 physicians, 4 NPs, 3 PAs, 2 pharmacists, and 2 social workers. Each participant developed and implemented an action-learning project focused on improving HIV-related care processes.



Project themes included:

1. Strengthening health maintenance and cancer screening workflows.
2. Improving patient communication to support understanding, engagement, and follow-through.
3. Addressing social determinants of health through screening, referral pathways, and community partnerships.
4. Enhancing care coordination strategies across disciplines and settings.

Participants stated, "*it was empowering to lead a team-based effort to increase anal cancer screenings*," and "*we worked as a group to identify ways to improve young engagement with doxyPEP*," and "*it was inspiring to see staff recognize the importance of gaining trauma-informed communication skills*."

CONCLUSIONS

Over four years, ACTHIV® ChangeMakers has evolved from a primarily leadership-focused model to an integrated leadership + implementation science approach that supports clinicians in designing, executing, and sustaining pragmatic care improvements. Centering informal leadership alongside implementation science skill-building appears to be especially well-suited for HIV care environments where strengthening leadership skills, adapting innovations to local contexts, and leveraging interprofessional collaboration. Future programs will continue to build on these themes.

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ACTHIV ChangeMakers

Closing the care gap: Optimizing HIV primary care through targeted outreach at a primary care clinic

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UMass Chan MEDICAL SCHOOL

Background

- HIV primary care is essential in the modern ART era, enabling people living with HIV to maintain long-term health, prevent disease progression, and eliminate transmission through consistent engagement and uninterrupted treatment. Providing comprehensive, patient-centered, and stigma-free care is key to achieving optimal outcomes.
- Our practice may have gaps in primary care services for people with HIV, particularly in preventive care such as immunizations, cancer screenings, and other guideline-based measures. Despite having around 20 primary care clinicians, only about 20 patients with HIV are represented across panels, suggesting possible under-identification or limited engagement in care
- In an evolving political and funding landscape, it is increasingly important for primary care clinicians to feel confident providing comprehensive, HIV-informed care, including preventive services, lipid monitoring, and chronic disease management

Method

This project was conducted in three phases.

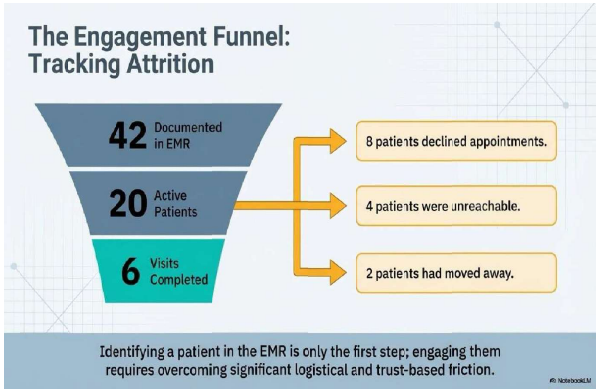
Phase 1- an initial list of 42 patients with HIV in the electronic medical record (EMR) was refined to 20 active patients after excluding those no longer followed at our site. A staff member was trained for outreach, and two resident physicians assisted with chart review, data analysis, and documentation.

Phase 2- patients were contacted and offered a one-time consultation with a board-certified family physician and HIV specialist to address primary care gaps, with reassurance that existing relationships with their primary care provider (PCP) and infectious disease (ID) specialist would remain unchanged; PCPs were informed prior to outreach. An additional referral pathway from ID was planned but did not occur due to logistical challenges.

Phase 3 - Residents used a one-page preventive care guide for chart review. Care gaps were addressed during visit, and follow-up recommendations were communicated to PCPs.

Objectives

- Optimize primary care delivery and close preventive care gaps for people with HIV at our practice site.
- Increase the number of patients with a diagnosis of HIV receiving care in our practice.

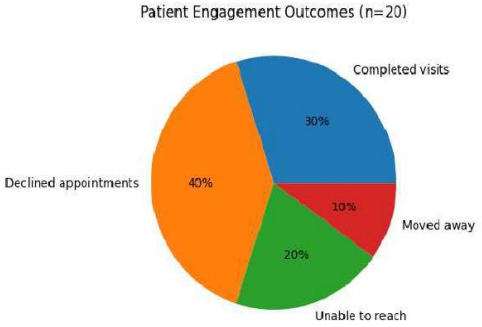


Conclusion

- This project demonstrated that a structured, team-based outreach model can identify and address meaningful preventive care gaps for PWH in primary care. Although only 6 of 20 patients completed visits, participants had multiple gaps identified and closed.
- These findings highlight both the potential to improve care quality through focused interventions and the ongoing challenges of patient engagement.

Results

Of the 20 patients at our practice site, 6 successfully completed visits, 8 declined appointments, 4 unable to reach, 2 moved away.



Key Insight

A structured, team based outreach and consultation model can work in a primary care setting. However, Future QI initiatives and funding must target patient trust, outreach logistics, and engagement barriers just as aggressively as clinical training. Improved care quality depends largely on solving the engagement equation

Acknowledgements

- Faculty colleagues who allowed one-time consultations with their patients and were receptive to recommendations Department leadership—Dr. Stephanie Carter-Henry (Medical Director), Jessica Fletcher (Office Supervisor), and Kori Berardino (Office Manager)—for their support in navigating logistics
- Project team for their dedication and hard work throughout the project

ACTHIV CHANGEMAKERS: PERSON-FIRST LANGUAGE TO REDUCE STIGMA AND SUPPORT IDENTITY-AFFIRMING CARE

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Background

Person-first language (PFL) emerged from the civil-rights era to promote dignity and reduce stigma. In HIV care, stigmatizing communication undermines trust and creates barriers to engagement.

> *"HIV stigma negatively affects one's ability to care for the virus, depleting determinants of health like relationships and trust." (Hyams et al, 2018)*

Default clinical documentation often relies on unspoken "norms" regarding race, orientation, and ability, reinforcing bias.

Objective

To increase consistent use of person-first, identity-affirming language in ID settings by:

- Training staff to replace stigmatizing terms.
- Embedding PFL prompts in the EMR (EPIC).
- Implementing "I am..." dialogue frameworks.

Methods

1. **In-service Training:** Physicians, nurses, and staff in ID departments.
2. **Clinical Audits:** Review of EMR discharge/progress notes for deficit-based phrasing.
3. **Digital Tools:** Development of EPIC "SmartLists" for real-time terminology support.

Clinical Transformation: The "I AM" Approach

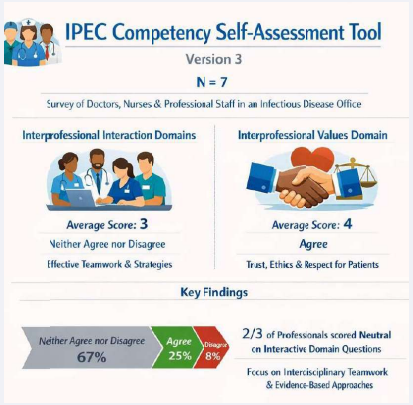
OLD WAY: IMPLICIT LABELING

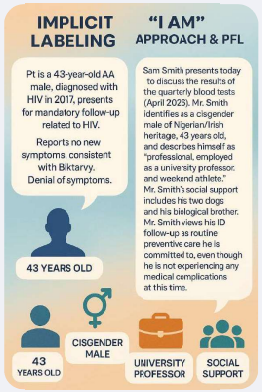
"Pt is a 43-year-old AA male, diagnosed with HIV in 2017... Denial of symptoms."

NEW WAY: PFL "I AM" APPROACH

"Sam Smith identifies as a cisgender male of Nigerian/Irish heritage, 43 years old, and describes himself as a "professional, university professor, and weekend athlete." Mr. Smith views his follow-up as routine preventive care..."

IDENTITY VOICE RESPECT





EPIC Electronic Health Record

User SmartList – Person First Language

- BIPOC (Black, Indigenous & Other People of Color)
- HIV acquisition
- Living with HIV
- Sex without Barriers
- "Are you comfortable here?"

Integrating grid directly into EMR reduces cognitive burden for providers and ensures consistency.

Bilingual PFL Reference

AVOID	PFL SUGGESTION	(SPANISH)
HIV Infected	**Living with HIV**	*Vivir con VIH*
Unprotected Sex	**Sex without barriers / PrEP**	*Sexo sin barreras / con PrEP*
HIV Infection	**HIV Acquisition**	*Adquisición del VIH*
Defining by disease	**Person experiencing...**	*Persona que experimenta...*

Conclusion

Embedding PFL into training and EMR documentation is a **practical, low-cost strategy** to reduce stigma and advance equitable care. By addressing outdated "default" descriptors, clinicians can significantly improve patient trust, experience, and retention in the HIV care continuum.

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ACTHIV ChangeMakers: Building Group Nutrition Education at Vivent Health+TPAN, an HIV Healthcare Center

Cori Blum, MD, AAHIVS, Elizabeth Tanner, MSW, Andrew K. Miller • Vivent Health+TPAN, Chicago, IL

BACKGROUND

People living with HIV benefit from nutrition education and access to healthful foods to reduce inflammation and chronic disease risk, yet many face barriers:

- Economic stress and limited nutrition knowledge
- Limited access to dedicated nutritionists
- Gap between food pantry services and nutrition education

Vivent Health+TPAN in Chicago has an on-site food pantry but lacks dedicated nutritionists. The ACTHIV ChangeMakers program enabled an Action Learning Project to address this gap.

OBJECTIVE

To improve access to nutrition education at Vivent Health+TPAN through collaborative engagement with peers, mentors, clients, colleagues, and community partners.

FOOD INSECURITY DATA

75% Used food pantry in past month

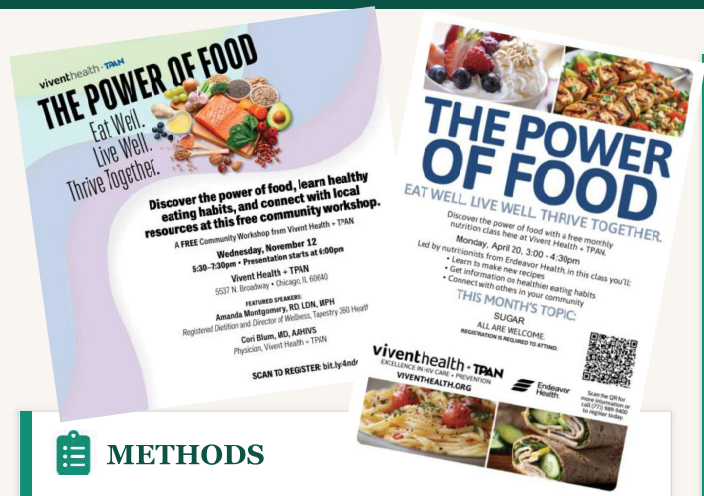
50% Used pantry 2–3 times/month

63% Worried about running out of food

Fruit & vegetable consumption varied from more than once daily to once monthly across participants.

Acknowledgments

ACTHIV ChangeMakers Program faculty, mentors, and peer cohort members; Vivent Health+TPAN clients and staff; community partners.
Contact: coriblum@viventhealth.org



METHODS

1. **Needs Assessment**
   Lead physician surveyed clients on desired nutrition topics and consulted nutritionists at other Vivent Health sites
2. **Public Community Workshop**
   Hosted a workshop featuring an FQHC nutritionist and community food organizations to build partnerships.
3. **Pilot Program Launch**
   Partnered with a community hospital system to launch a 6-month pilot of monthly nutrition and cooking classes (February 2026).
4. **Class Structure**
   Each class features registered dietitians teaching a specific topic (e.g., heart-healthy nutrition, reading food labels, shopping on a budget), cooking demonstration, tasting, and recipe sharing.
5. **Recruitment & Outreach**
   First class: 90 clients invited via EHR messaging; 14 RSVPed, 9 attended. Future outreach includes EHR messages, verbal invitations, and posted flyers.
6. **Evaluation**
   Participants complete pre- and post-series surveys; staff continue to gather feedback throughout the pilot.

RESULTS

Participants expressed interest in practical nutrition skills, improving access to healthy foods, and building community.

"Looking to make healthier choices to manage my health and weight"
"Hoping to learn more about processed foods and the damage they do in the long term"
"Tips on how to eat better"
"Improve my liver"

Pre-series survey highlights:

- 75% had used food pantry or free meal programs in the past month
- 50% had used pantry services 2–3 times per month
- 63% reported worrying about or running out of food
- Fruit/vegetable consumption ranged from >1×/day to 1×/month

PILOT CLASS ATTENDANCE
90 invited → 14 RSVPed → 9 attended

DISCUSSION / CONCLUSIONS

In the absence of on-site dietitians, group-based nutrition and cooking classes offer feasible, integrated nutrition education and peer connection.

Implementation Challenges:

- Navigating organizational approvals and delayed promotional materials
- Limited physical space options for group classes

Next Steps:

- Pilot evaluation will inform sustainability and potential expansion toward integrated dietitian-led care
- Refine recruitment strategies to improve attendance rates
- Explore integration of routine dietitian-led assessments

vivent health · TPAN
EXCELLENCE IN HIV CARE + PREVENTION

ACTHIV CHANGEMAKERS
AN ACTION LEARNING PROJECT

ACTHIV ChangeMakers 2025-26: Pilot Testing and Focus Group Evaluation of Evidence-Based HIV 'Get Tested' Preventive Care Checklists Across San Diego HIV Community Organizations

A Guide for People Living with HIV and Providers to Ensure Recommended Tests and Vaccinations Are Completed

Ellen Wu[1], Jerry Turner[2,3], Jason Cuneo, BA[2,3,4], Wanda London, LCSW[2,3,5], Jen Lotheridge, LCSW[2,3,6], Jim Corbett[2,3], Joseph Caperna, MD[1]

[1] UCSD Herbert Wertheim School of Public Health, [2] San Diego HIV Consortium, [3] POZabilities, [4] The SD LGBT Center, [5] Christies Place, [6] California Baptist University

BACKGROUND

The Challenge

Comprehensive preventive care for PLWH remains deeply fragmented across healthcare systems. People routinely fall through gaps between specialist visits and primary care, missing critical screenings and vaccinations.

Federal Policy Uncertainty

Recent policy shifts — including CDC noting its website is "being modified to comply with President Trump's Executive Orders" — increase uncertainty around centralized recommendations, underscoring the need for locally controlled, community-driven solutions (CDC, 2025).

Objective

To synthesize preventive care guidelines for people living with HIV and pilot-test a consumer-facing preventive care checklist for usability, feasibility, and perceived value across community HIV settings.

IMPACT

Traditional preventive care tools are provider-facing. This initiative shifts access and agency to PLWH—enabling informed participation and shared decision-making in clinical encounters.

Community Setting

San Diego HIV Community Consortium (SDHIVCC) is a grassroots coalition including POZabilities, Christie's Place, Being Alive San Diego, and the San Diego LGBT Center, serving thousands of PLWH across San Diego County.

Figure 2: Focus Group Respondents (n=108)

"Get Tested" Respondants	Associated NGO with on-going meetings	Weblink	N	Gender	Age	Race/Ethnicity
HIV Science Updates	The San Diego HIV Community Consortium monthly	sdhivc.org	17	M=9, F=5, T=1	40-81 (avg 65)	W=10, B=4, L=3
"What's newest in HIV 2025" limited 8 week course for PLWH	The San Diego HIV Community Consortium monthly	sdhivc.org	7	M=2, F=4, T=1	45-84 (avg 60)	W=2, B=4, L=1
Aging with HIV	POZabilities weekly	https://www.pozabilities.org	17	M=17	60-81 (avg 70)	W=17
HIV Yoga	Serenity Yoga weekly	https://www.facebook.com/SerenityYogaClass	12	M=8, F=3, T=1	50-75 (avg 63)	W=7, B=2, AA=2, L=1
LatinX Youth	Las Manzanitas/The San Diego LGBT Center monthly	https://thecentersd.org/events/las-manzanitas/	8	M=8	20-44 (avg 30)	L=8
Women Living with HIV	Christie's Place monthly	https://christiesplace.org	5	F=5	40-70 (avg 50)	B=3, W=1, L=1
LatinxMSM	Acción Positiva/The San Diego LGBT Center monthly	https://thecentersd.org/events/accion-positiva-1/	10	M=10	20-65 (avg 43)	L=10
Private practice, other practice, other institutions			32	M=20, F=2, T=1	20-80 (avg 56)	W=19, B=8, AA=4, L=3, NA/PI=1
TOTAL			**108**	**M=74, F=19, T=4**	**20-84 (avg 55)**	**W=56, B=21, L=27, AA=6, NA/PI=1**

Quote from LatinxMSM: "Most participants liked the form, though many lacked the basic health knowledge to complete it independently and needed explanation from the physician at our focus group. With guidance, everyone completed the form in 15 minutes. This proved to be an excellent educational tool. Our group consists primarily of Spanish speakers who had no suggestions for improving the translation, so I will use your Spanish version as written"

METHODS

TECHNICAL CHALLENGES (building the checklist)	ADAPTIVE CHALLENGES (provider resistance & power dynamics)

Phase 1—Guideline Synthesis

Conducted a structured comparative analysis of 9 authoritative guidelines (AAHIVM, IDSA, CDC, DHHS, USPSTF, WHO, EACS, AAFP, ACP) using a predefined matrix. Observed ≥80% concordance across 29 preventive care domains.

Phase 2—Checklist Development

Developed a consumer-facing checklist covering 17 health conditions and 14 vaccinations. HIV-specific recommendations highlighted in red — differentiated from general population guidelines.

Phase 3—Community Pilot, Jan 2026

Piloted across 7 San Diego HIV support groups with 108 PLWH participants. Collected anonymous provider feedback via structured survey (n=16). Average completion time: ~15 minutes with facilitator support.

Phase 4—Focus Group Evaluation

Conducted facilitator-led focus groups assessing usability, comprehension, and equity barriers. Community health educators also assisted with session facilitation.

Figure 1: Guideline Comparison Matrix (9 guidelines, 29 categories)

Category	Measure	AAHIVM	IDSA	CDC	DHHS/NIH	USPSTF	WHO	EACS	AAFP	ACP	PLWH Recommendation	General Pop Recommendation
Vaccinations	Influenza (Annual)	1	1	1	0.5	0.5	1	1	0.5	0.5	All PLWH: Annual IIV (LAIV contraindicated); high-dose or adjuvanted preferred ≥65	All ≥6mo: Annual; high-dose/adjuvanted preferred ≥65
	COVID-19	1	1	1	0.5	0.5	1	1	0.5	0.5	All PLWH: Per current CDC schedule; additional doses if immunocompromised	Per CDC schedule by age/risk
	Pneumococcal	1	1	1	0.5	0.5	1	1	0.5	0.5	All PLWH ≥19: PCV20 or PCV21 alone, OR PCV15→PPSV23 (≥8wk interval)	≥50 (Oct 2024): PCV20/21; or ≥65; 19-49 if risk factors
	Hepatitis A	1	1	1	0.5	0.5	1	1	0.5	0.5	All non-immune PLWH: 2-dose series	Risk-based (MSM, travelers, chronic liver disease, drug use)
	Hepatitis B	1	1	1	0.5	0.5	1	1	0.5	0.5	All non-immune PLWH: 3-dose series; check anti-HBs; revaccinate if <100 mIU/mL	Universal 19-59; ≥60 risk-based or by preference
	HPV (routine ≤26; SCDM 27-45)	1	1	1	0.5	0.5	1	1	0.5	0.5	PLWH 9-26: Routine 3-dose series; 27-45: Shared clinical decision-making	9-26: Routine; 27-45: SCDM based on benefit likelihood
	Tdap/Td	1	1	1	0.5	0.5	1	1	0.5	0.5	Same as general population	Tdap once; Td or Tdap every 10 years
	Zoster/Shingrix (≥19 if immunocompromised)	1	1	1	0.5	0.5	0.5	1	0.5	0.5	PLWH ≥19 with CD4 ≥200: 2-dose RZV series (2-6mo apart)	≥50: 2-dose RZV series
	Meningococcal ACWY	1	1	1	0.5	0.5	0.5	1	0.5	0.5	All PLWH: 2-dose MenACWY primary series (≥8wk apart); boost q5yr	Risk-based only (college, asplenia, complement deficiency, travel)
STI Screening	Syphilis	1	1	1	1	1	1	1	1	1	All PLWH: At entry to care + at least annually; more frequent if high-risk behavior	Risk-based (MSM, multiple partners, sex workers)
	Gonorrhea/Chlamydia	1	1	1	1	1	1	1	1	1	All PLWH: Annual 3-site NAAT (pharyngeal, rectal, urogenital) based on exposure; more frequent if risk	Women <25: Annual; others risk-based; 3-site for MSM
	Hepatitis C	1	1	1	1	1	1	1	1	1	All PLWH: At entry to care; annually if ongoing risk factors; when clinically suspected	Universal one-time 18-79; repeat if ongoing risk
Cancer Screening	Cervical Cancer	1	1	1	0.5	1	1	1	0.5	0.5	At HIV diagnosis; annual ×3 then per results (may extend to q3yr after serial normal/negative)	21-29: q3yr cytology; 30-65: q3yr cytology OR q5yr HPV/cotesting
	Colorectal Cancer	0.5	0.5	0.5	0.5	1	0.5	0.5	1	1	Same as general population 45-75 per USPSTF	45-75: Colonoscopy q10yr OR FIT annually OR other approved methods
	Breast Cancer	0.5	0.5	0.5	0.5	1	0.5	0.5	1	1	Same as general population	40-74: Biennial mammography (USPSTF Grade B)
	Lung Cancer (LDCT)	0.5	0.5	0.5	0.5	1	0.5	0.5	1	1	Same as general population	50-80 with ≥20 pack-year history (current or quit <15yr): Annual LDCT
	Anal Cancer/HSIL Screening	0.5	1	1	1	0	0	1	0	0	MSM/TW ≥35 (others ≥45 with risk): Annual DARE; anal cytology→HRA when available	Not routinely recommended (no USPSTF recommendation)
	Hepatocellular Carcinoma	0.5	1	0.5	0.5	0	0.5	1	0.5	0.5	HBV/HCV coinfection or cirrhosis: q6mo US ± AFP	Cirrhosis: q6mo US ± AFP
Prevention	Tobacco Cessation	1	1	1	1	1	1	1	1	1	Same as general population Ask, advise, refer, pharmacotherapy	All tobacco users: Behavioral counseling + pharmacotherapy
	U=U Counseling	1	1	1	1	0	1	1	0.5	0.5	All PLWH: Counsel that Undetectable = Untransmittable when VL suppressed	N/A
	Depression Screening	1	1	1	1	1	1	1	1	1	All PLWH: PHQ-2/PHQ-9 at entry and periodically	All adults: Screen when adequate systems in place (USPSTF Grade B)
	Alcohol Misuse Screening	1	1	1	1	1	1	1	1	1	All PLWH: AUDIT-C at entry and periodically	All adults: Screen + brief intervention (USPSTF Grade B)
	CV Risk Assessment + Statin	1	1	0.5	0.5	1	1	1	1	1	All PLWH: ASCVD risk assessment; consider statin per REPRIEVE (benefit even at lower risk)	ASCVD 10-yr risk; statin if ≥7.5-10%
	Latent TB Screening	1	1	1	1	0.5	1	1	0.5	0.5	All PLWH: TST or IGRA at entry; repeat if initial negative and CD4 rises >200; annual if ongoing risk	Risk-based (immigrants, congregate settings, HCW, contacts)
Aging	Frailty Screening	1	1	0.5	0	0	1	1	0.5	0.5	PLWH ≥50: Validated frailty assessment (e.g., FRAIL scale, gait speed)	≥65: Per geriatric assessment; no universal USPSTF rec
	Cognitive Screening (HAND)	1	1	0.5	0	0	1	1	0.5	0.5	PLWH ≥50 or with symptoms: Screen for HIV-associated neurocognitive disorders	≥65: No routine screening recommended (USPSTF I statement)
	Bone Density (DXA)	1	1	0	0	0.5	0	1	0.5	0	Postmenopausal women; men ≥50 with risk factors (TDF use, fracture history, etc.)	Women ≥65; men ≥70; postmenopausal with risk factors (USPSTF Grade B women)
	Fall Risk Screening (Formal Assessment)	0	0	0	0	0.5	0.5	1	0	0	PLWH ≥65 or with risk factors: Formal fall risk assessment	≥65: Exercise interventions recommended; multifactorial for high-risk (USPSTF Grade B)
	Polypharmacy Review	1	1	0	0	0	0.5	1	0.5	0.5	All PLWH on multiple medications: Annual review for interactions, deprescribing	General geriatric principle; no specific USPSTF recommendation

"Get Tested" Checklist: https://www.sdhivc.org/get-tested-project/

Key:

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RESULTS

80% Guideline consensus across 29 categories

108 PLWH participants (7 groups)

16 Providers surveyed anonymously

KEY OBSERVATION: Provider reluctance emerged as a recurring theme during implementation. Several non-participating clinicians acknowledged the checklist's clinical value, suggesting perceived role boundaries and professional power dynamics may influence adoption. The barrier is systemic, not substantive.

Most Missed Screenings: Most missed screenings included lung cancer CT, cognitive assessment, and anal Pap—highlighting critical gaps in HIV-specific care delivery across all seven pilot sites.

Most Missed Vaccinations: Most missed vaccinations included HPV, meningococcal, Mpox, and pneumococcal.

Equity Consideration: Participants without electronic medical record (EMR) access required facilitator support, highlighting digital health equity barriers.

Task-Sharing Success: Community health educators successfully adopted the tool, demonstrating scalability beyond traditional clinical settings.

HIV-Specific Care Gaps: Pneumococcal/shingles (≥19 vs. ≥50), meningococcal (universal vs. risk-based), anal cancer screening (yearly vs. general population), osteoporosis (50+ vs. 65+), cognitive screening (universal vs. symptomatic only).

CONCLUSIONS

First systematic synthesis comparing preventive care recommendations for PLWH across nine major guidelines into a single consumer-facing checklist.

Community-driven tools work and demonstrates the potential for locally governed tools to support evidence-based preventive care during policy instability.

Future partnerships planned with AIDS Education and Training Center and San Diego County Public Health.

"What we need now is to implement this." — PLWH participant

ACTHIV ChangeMakers: Applying Adaptive Leadership to Develop Patient-Facing HIV Preventive Care Checklists Through a Community-Driven Process

A guide for people living with HIV (PLWH) and providers to ensure recommended tests and vaccinations are completed

Ellen Wu[1], Jerry Turner[2,3], Jason Cuneo, BA[2,3,4], Wanda London, SW, WLWH[2,3,5], Jen Lotheridge, BSW, WLWH[2,3,6], Jim Corbett[2,3], Joseph Caperna, MD[1]

1. UCSD Herbert Wertheim School of Public Health 2. San Diego HIV Consortium 3. POZabilities 4. The SD LGBT Center 5. Christies Place 6. California Baptist University

BACKGROUND

Traditional preventive care tools are provider-facing, reinforcing a model where clinicians control health information and decision-making.

Using an Adaptive Leadership framework, we developed a **patient-facing preventive care checklist** that shifts access, understanding, and agency to people living with HIV (PLWH).

This work distinguishes between:

TECHNICAL CHALLENGES
(building thechecklist)

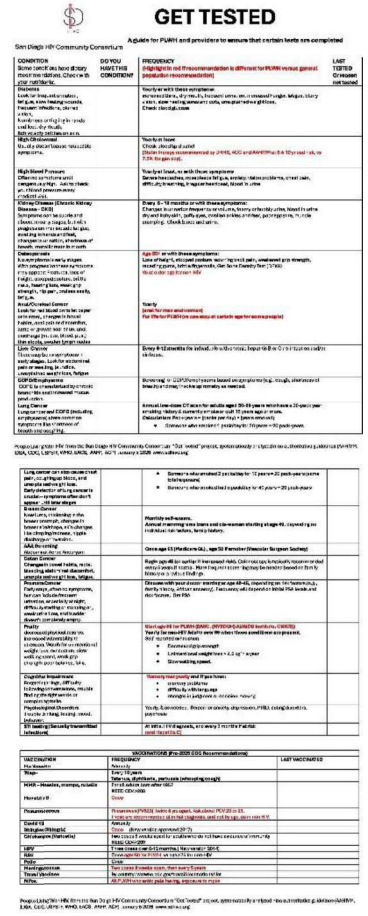
ADAPTIVE CHALLENGES
(addressing providerresistance and powerdynamics)

METHODS

An 8-month, community-driven project in San Diego, California progressed through four phases:

- **Phase 1—Development:** Reconciled 9 preventive care guidelines
- **Phase 2—Expert & Community Input:** Navigated provider resistance
- **Phase 3—Pilot Study:** 108 people living with HIV (PLWH) and 16 providers surveyed
- **Phase 4—Partnership Development:** Formalized the San Diego HIV Community Consortium (SDHIVCC) coalition

Technical work enabled adaptive progress: guideline analysis created cross-sector dialogue, and community piloting built organizational trust.



GET TESTED

A guide for PLWH and providers to ensure that certain tests are completed

San Diego HIV Community Consortium

"Nothing about us without us."

San Diego Community Consortium

RESULTS

100%
PLWH Acceptance

62%
Physician Acceptance

KEY OBSERVATION: Provider resistance reflects professional power dynamics—not concerns aboutquality.

Even physicians who declined participation acknowledged the checklist's value. **The barrier is systemic, not substantive.**

RESULTS: Strong community engagement and high PLWH acceptability; more variable physician acceptance.

Academia, community organizations, and grassroots partners collaborated to address complex, fragmented care guidelines.

Participants use the checklist to prepare for visits, ask informed questions, and identify missed tests and vaccinations.

IMPACT: This project shifts preventive care from a provider-controlled model to a **shared, patient-centered approach**.

PLWH are better equipped to understand their care, track what is needed, advocate for themselves in clinical settings

FUTURE DIRECTIONS: Future initiatives should apply Adaptive Leadership approaches to reexamine how clinical information is shared, understood, and acted upon.

Scaling patient-facing tools can improve engagement, trust, and completeness of HIV preventive care.

"What we need now is to implement this."- PLWH

ACTHIV® ChangeMakers 2025-26: Using Motivational Interviewing to Improve Medication Adherence Among People Living with HIV Who Are Not Virally Suppressed

Erika Dixon, LCSW

Background

Despite significant advances in antiretroviral therapy (ART), some People Living with HIV (PLWH) remain unsuppressed due to inconsistent medication adherence. Common barriers include medication fatigue, stigma, mental health concerns, substance use disorders and competing life demands. Motivational interviewing (MI) is a collaborative, person-centered counseling method designed to strengthen an individual's motivation and commitment to change. A pilot project was implemented to utilize MI techniques for PLWH who are virally unsuppressed at Penn Community Practice Infectious Diseases Department (PCID).

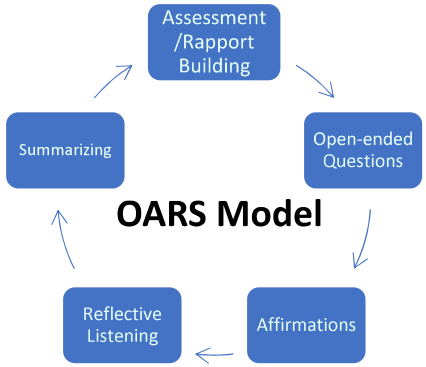
Objective

This pilot project aims to explore more effective ways of communication and enhance patient engagement by utilizing motivational interviewing skills and techniques.

Methods

Fifty patients at PCID were identified with unsuppressed viral loads in October of 2025. The clinic social worker conducted semi-structured interviews with patients that focused on open-ended questioning, reflective listening, affirmation, and summarization to enhance patient-driven conversations. Observational notes were collected to identify common themes concerning adherence barriers, motivation and changes in attitudes toward medication-taking behaviors. Four of the fifty patients were interviewed, and more are planned. The Adaptive Leadership Framework helped to identify the need of utilizing MI within monthly viral load suppression group.

Case Illustration: 24 y/o female diagnosed in 10/2025 who intermittently takes Biktarvy. No known co-morbidities. Viral Load: 3,950



Question:	Response:
What are your beliefs about taking medication?	Taking my meds is important but I don't want to throw up from taking them.
What is the main barrier that keeps you from staying consistent?	Working long hours and being scared that I will throw up while working.
What is one small step to help you stay on track?	Getting a new medication.
What ways can I help support you?	Discussing new meds because this one makes me throw up and it is painful.
What are some pros and cons of taking your medication?	Being healthy and getting sick.

Preliminary Results

Participants mentioned emotional fatigue from daily life stressors, stigma surrounding diagnosis and difficulties with navigating comorbid disorders as obstacles to medication adherence. As a result of the case described, patient and provider engaged in an informed conversation about ART options. Although patient continues to be inconsistent, after provided education, they were given the autonomy to discuss adherence struggles freely. The patient reported feeling "heard" and more comfortable. As interviews continue, quantitative adherence and viral load data collection are forthcoming.

Conclusions

Early findings suggest that MI can strengthen patient engagement amongst PLWH who struggle with viral suppression. MI allows the patient and provider the opportunity to communicate openly and collaboratively, helping the patient explore thoughts and feelings regarding medication adherence. Patients have increased motivation for change, improved engagement and reduced resistance. Integrating MI into the HIV care setting has the potential to advance patient-centered approaches and improve health outcomes, which will contribute to ending the HIV epidemic.

Heifetz. R, Grashow. A, Linsky. (2025). *The Practice of Adaptive Leadership*

ACTHIV® ChangeMakers 2025-26: Development of a Standardized Care Pathway for Patients Newly Diagnosed with HIV in a Hospital System

Mary E. Ferranti, MD[1], Anna Russell[2], Samantha Boyd[3], Adam Williams, MPA[3], Alexis Schwartz, LSW[2], William Short, MD, MPH[1]

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Background

- With universal HIV screening recommendations, new diagnoses continue to occur across healthcare settings.
- Limited provider familiarity with recommended initial evaluation and linkage-to-care practices may delay antiretroviral therapy initiation and increase patient distress at the time of diagnosis.

Objectives

- To address this, we are developing a standardized, health system–wide pathway to support the evaluation and linkage to care for patients newly diagnosed with HIV, particularly in the hospital setting.

Methods

- We are developing a standardized clinical pathway to support providers outside of Infectious Diseases (ID) in the management of newly diagnosed HIV.
- The pathway outlines recommended initial diagnostic evaluation to facilitate timely outpatient antiretroviral therapy (ART) initiation. It incorporates a multidisciplinary approach leveraging an established HIV Navigation team to ensure rapid linkage to care.
- The pathway directs providers to notify both the HIV Navigation team and Infectious Diseases consult service at the time of diagnosis to establish connection to HIV care while in the inpatient setting and ensure seamless transition to outpatient follow-up.

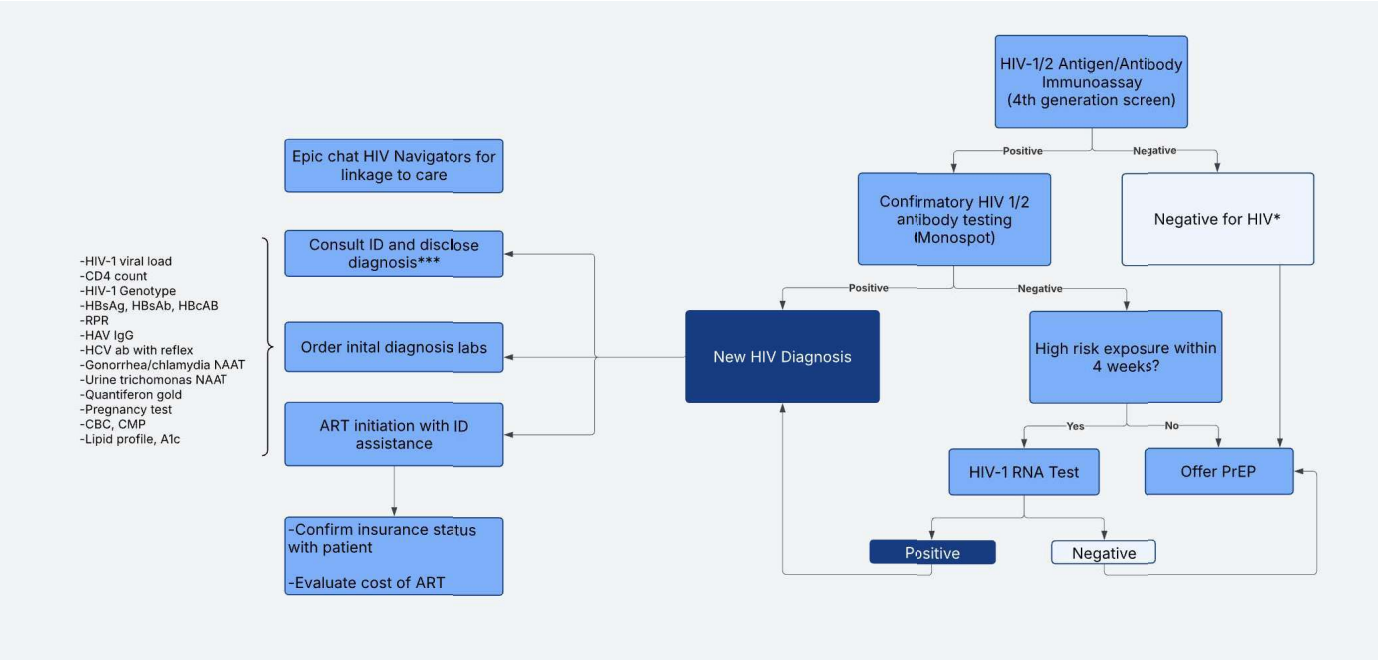

Figure 1: Pathway for newly diagnosed patients with HIV

Projected Impact

- Following the eventual implementation of the pathway, we will:
  - Evaluate the pathway's impact on linkage to care by quantifying the proportion of newly diagnosed patients who attend an initial outpatient ID appointment.
  - Assess the proportion of patients who had inpatient ID consultation before diagnosis and examine whether this early exposure is associated with ID appointment attendance.
- Conduct brief patient interviews to explore perceptions of early ID engagement and its influence on follow-up attendance
- Evaluate completion of recommended baseline laboratory work prior to the initial ID visit and obtain provider feedback regarding the clinical utility of this pre-visit workup.
- A standardized health system–wide pathway for the evaluation and linkage to care of patients newly diagnosed with HIV has the potential to streamline diagnostic evaluation, support providers across disciplines, and improve continuity of care for individuals entering HIV care.

ACTHIV Changemakers 2025-2026: Increasing PreP Counseling and Prescribing by Reproductive Health Providers

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1. Erie Family Health Centers, 2. University of Chicago, 3. Northwestern University, 4. Ann and Robert H. Lurie Children's Hospital

Background

Across the U.S., uptake of Preexposure Prophylaxis (PreP) among cisgender women remains significantly lower than among cisgender men and transgender women. In 2024 the PrEP-to-need ratio was 7.3 in people who identify as female compared to 16.9 in people who identify as male. Our organization has partnered with Power UP (PrEP Optimization Among Women to Enhance Retention and Uptake), a study out of the University of Chicago that is focused on increasing PrEP uptake among cisgender women of color. In May 2025, we launched a Best Practice Advisory (BPA) to alert providers when a patient had a GC/CT/trichomonas infection within the past six months, identifying them as a candidate for PrEP. The BPA included a link to a PrEP SmartSet with labs and medications as well as options to indicate patient refusal or provider postponement. Early review showed most alerts occurred during Reproductive Health (RH) visits (though total patient number is lower due to multiple visits per patient), yet RH providers were less likely than other providers to indicate that they counselled on PreP.

Prior to intervention

	Patient number	% counseled
Reproductive health	177	10.7%
Family Medicine	212	14.2%

Objectives

We aimed to better support RH providers and increase their comfort and engagement in prescribing PrEP to at-risk patients.

Methods

We used an adaptive leadership model to discuss the barriers for RH providers counseling on and prescribing PreP. In conversations with RH providers and leaders we identified that the biggest barriers were lack of awareness of the BPA functionality, lack of comfort prescribing PreP, and lack of time in visits for counseling.

Results

We implemented a two-pronged strategy.

The technical intervention updated the BPA to include a button allowing providers to directly notify the PrEP navigation team when a patient expressed interest in learning more. Our PreP team would then reach out to the patient directly.

The adaptive intervention involved targeted education session for RH and prenatal providers. This session addressed HIV risk and disparities among cisgender women, reviewed PrEP recommendations and prescribing guidance, and clarified BPA functionality.

Reproductive Health Providers

	Patient number	% counseled
Prior to intervention	177	10.7%
After intervention	153	20.9%

A very basic review suggested that rates of PreP counseling increased during Reproductive Health visits after a targeted education session and an update of the EMR Best Practice Advisory. Anecdotal reports also suggest increased numbers of patients being referred to the PreP navigation team and HIV certified providers receiving more questions about PreP prescribing.

Conclusions

Targeted education and EMR workflow support for RH providers may be one way to increase PreP counselling and uptake in cis-gender women.

Next Steps

I hope to complete a formal study to compare PrEP prescribing rates before BPA implementation, after the initial launch, and following the update. Chart reviews will capture counseling not documented through the BPA. We plan to include all provider types and hope to evaluate gender differences as well as pregnancy status.

ACKNOWLEDGMENTS

Thanks to Lisa Vasquez, Elizabeth Tumiel, and Adileny Botello

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Contact: Jacqueline McSparron PA-C, AAHIVS jmcsparron@eriefamilyhealth.org

ACTHIV® ChangeMakers 2025-26: Youth-Informed Adaptive Leadership to Advance Doxycycline Post-Exposure Prophylaxis Uptake

Gina Sabbatini, Megan Wilkins, Susan Carr, Katherine Knapp, Chris Sinnock, Nehali Patel

St. Jude Children's Research Hospital

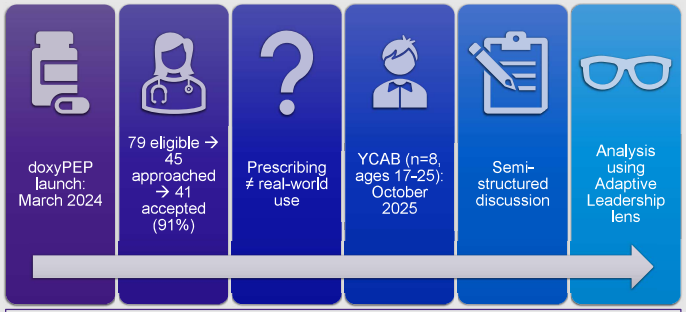
BACKGROUND

- Rising rates of bacterial sexually transmitted infections (STIs) among youth represent a growing public health challenge in HIV prevention, with individuals ages 15-24 accounting for nearly half of reported cases.[1]
- Youth in Memphis, Tennessee experience disproportionately high STI and HIV incidence,[2] reflecting challenges faced by many urban HIV programs and underscoring the need for innovative prevention strategies.
- DoxyPEP reduces bacterial STIs[3-6] and may decrease downstream HIV risk.

OBJECTIVE

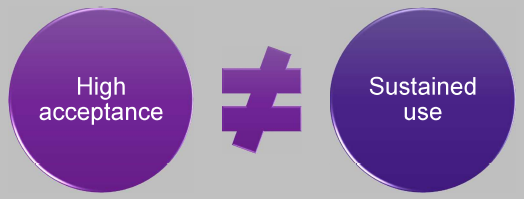
To examine youth perspectives shaping doxyPEP uptake through an Adaptive Leadership framework[7] – which distinguishes *technical solutions* from *adaptive challenges*

METHODS

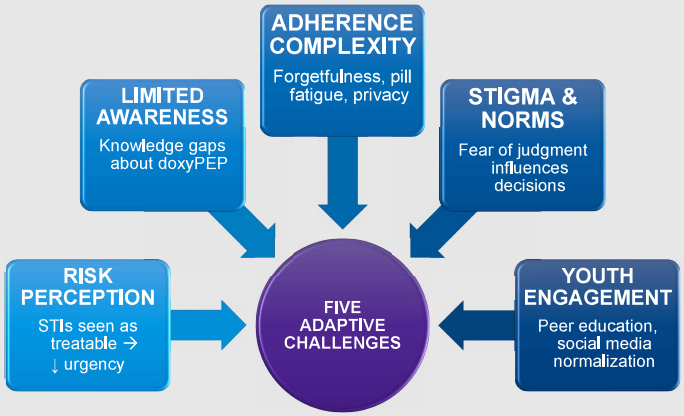


- Upon doxyPEP implementation in our youth HIV Clinic, clinicians observed a gap between initial prescription acceptance and adherence to instructed use.
- We convened an HIV status neutral Youth Community Advisory Board to explore perspectives and to identify adaptive challenges influencing doxyPEP uptake.

doxyPEP IMPLEMENTATION GAP



RESULTS



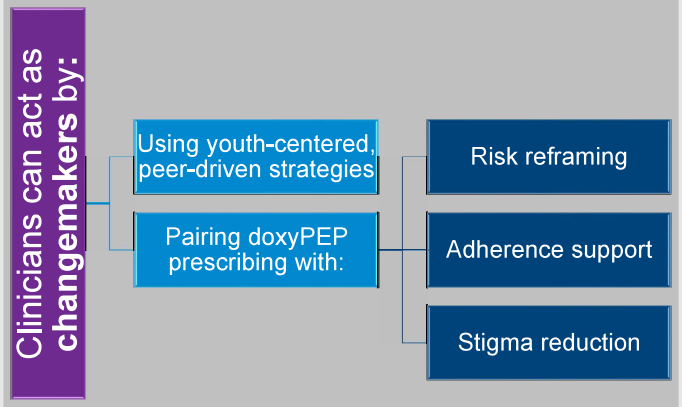
- Youth identified five interrelated adaptive challenges to doxyPEP use, with **low perceived STI risk most strongly limiting motivation for use**.
- Peer-led education and inclusive social media messaging were identified as essential approaches to address awareness, stigma, and adherence barriers.

CONCLUSIONS

- Youth perspectives suggest that doxyPEP innovation alone is insufficient for translation to optimal STI prevention outcomes.
- Successful doxyPEP implementation requires addressing adaptive challenges – including stigma, risk perception, and behavioral integration – that influence real-world uptake among youth.

INTRODUCING NEW BIOMEDICAL PREVENTION TOOLS REQUIRES MORE THAN TECHNICAL IMPLEMENTATION SUCCESS.

IMPLICATIONS FOR PRACTICE



Youth-informed adaptive strategies are critical for translating doxyPEP from access → sustained impact.

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Acknowledgments:

We gratefully acknowledge the Youth Community Advisory Board members for their invaluable insights, lived experience, and partnership in shaping this work and advancing youth-informed prevention strategies.

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St. Jude Children's Research Hospital
Finding cures. Saving children.

ACTHIV ChangeMakers: Real-Time Patient Impact Documentation During H.R. 1 Implementation in NYC HIV Clinics

2026

Stella Safo, MD MPH* | Ashley Latona MD** | Kimberly Harris MD**

*Montefiore Medical Center and Mount Sinai Health System, Bronx NY
**Department of Family and Social Medicine, Montefiore Medical Center

BACKGROUND

H.R. 1 created significant healthcare disinvestments affecting vulnerable populations, particularly people living with HIV (PLWH). While NY maintains some protections, critical gaps remain.

Frontline healthcare staff witness patient hardship daily but lack systematic mechanisms to document and communicate these impacts to policymakers.

OBJECTIVE

To develop the **Patient Impact Tool (PI-Tool)—**a rapid, efficient, standardized survey designed to document patient hardship and staff experiences resulting from policy changes in real-time clinical settings.

METHODS

Qualitative interviews with HIV clinic staff (n=8) across two NYC HIV outpatient clinics (social workers, practice managers, care coordinators, physicians).

Explored staff preferences for how to document and design the PI-Tool, given their busy clinical schedules.

Information from this first step will be used to develop a 2-4 minute web-based survey capturing patient hardships and staff experiences.

RESULTS: IDENTIFIED IMPACTS

Patient Impact

Staff revealed pervasive patient anxiety about HR-1, which one person described as *"complete calamity."* Anticipated hardships included:

- SNAP benefit losses
- Medication access barriers
- Housing instability and specialist care gaps

Staff Impact

Witnessing patient hardships contributes to staff feeling of burnout and moral injury. However, these feelings are offset by hopes that the PI-Tool can lead to improvements and supports for patients.

"Asking the entire health primary health system to do more with less is just going to contribute to burnout. Social workers might just be like, I can't take this anymore"

PI-TOOL DESIGN FEATURES

Format Preferences: Unanimous preference for 8-10 checkbox questions rather than lengthy narratives.

Workflow Respect: Intuitive design is necessary to motivate consistent engagement in busy clinics.

Policy Focus: Emphasizes capturing generalizable systemic failures rather than outliers.

PROJECT GOAL: At a time of restricted health resources for patients living with HIV, the Patient Impact tool systematically captures patients' hardships to inform clinic-based and policy-level improvements and support.

CONCLUSIONS

1. Alignment with Workflows: Real-time capture of patient experiences respects the extreme time limitations in clinical environments, making widespread adoption feasible.

2. Amplifying Voices: Generates systematic evidence of policy-driven hardship, giving weight to frontline lived experiences.

3. Evidence-Based Response: Informs resource allocation and proactive interventions at the clinic level, but also at the larger NYC city level.

SYSTEMIC IMPACT

By aggregating structured, real-time data, the PI-Tool moves beyond statistical reports to create actionable data built on lived experience that can drive policy change.

The PI-Tool equips advocates with immediate evidence to combat detrimental healthcare policy changes.

Efforts are underway to complete creation of the PI-Tool and deploy it to NYC HIV clinics for use.

***Staff willingness to use tool:* "I find these things (PI-tool) to be motivating. If I felt like what I was doing with capturing data was definitely helping many patients, then I would be motivated to use it."**

ACTHIV® ChangeMakers
2025-2026

Increasing Dental Adherence among Patients Living with HIV

Ashley Stines, DNP, FNP-C

BACKGROUND

- Patients with HIV are considered immunocompromised
- Dental care reduces the chance of oral opportunistic infection
- Barriers to dental care

PURPOSE

The purpose of this project is to increase dental adherence to the recommended dental guidelines among patients living with HIV at Maude L. Whatley Health Center

METHODOLOGY

- Sample Population: > 18 years of age
- Study Design: Convenience sample
- Barriers to receiving dental services assessed.
- Methods implemented to overcome common barriers.

IMPLEMENTATION

- IRB approval obtained
- Surveys distributed
- Initiatives were developed and implemented
- Educational handouts provided for participants
- Care coordination between HIV and dental visits
- Preferred method of communication addressed
- Transportation services identified
- Social worker involvement

SURVEY RESULTS

- Care coordination, financial restraints, fear of dentist, appointment reminders and inadequate transportation were identified as common barriers to dental care.

EVALUATION

Comparing dental adherence results before and after implementation in process.

PRACTICE IMPLICATIONS

- Decrease opportunistic oral infections
- Adherence is expected to improve health outcomes.
- Initiatives from this project can be applied to various appointment-based healthcare settings.

Enhancing Trauma-Informed Practices in LGBT+ HIV Care

Patrice Wade-Olson, DNP, RN, AGPCNP-BC

University of Detroit Mercy, College of Health Professions & McAuley School of Nursing

BACKGROUND

Trauma is highly prevalent worldwide, with approximately 70% of people experiencing some form of trauma throughout their life. Trauma can have significant lifelong impacts on health, including increasing risk of cancer, cardiovascular disease, depression, anxiety, and myocardial infarction.

For persons living with HIV, experiences of trauma can impact the ability to remain undetectable and are linked with lower CD4 counts. Trauma is also linked with worsened adherence and increased rate of HIV progression, as well as increased risk of intimate partner violence.

Higher rates of trauma are observed in persons living with HIV compared to those who are not. Trauma-informed care practices have been recommended to decrease experiences of re-traumatization within clinical settings.

70%

of people worldwide experience some form of trauma

METHODS

This intervention was conducted between October 2025 and February 2026 at a community health center. IRB approval was obtained in October 2025.

The principal investigator delivered a 60-minute professional development presentation titled "Utilization of Trauma-Informed Care in Daily Practice." Prior to the presentation, participants received an IRB-approved information sheet and completed a pretest survey.

Following the presentation, participants engaged in small group discussions to share perceptions of the organization's current TIC practices and offer suggestions for improvement. A posttest survey was then administered.

A total of 29 participants fully completed both surveys, including physicians, physician assistants, nurse practitioners, behavioral health therapists, case managers, early intervention specialists, and administrators.

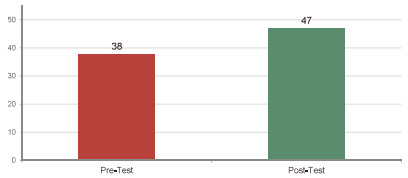
RESULTS

Paired Samples Statistics

	Mean	N	Std. Dev	Std. Error
PRE_Total	37.66	29	4.647	0.863
POST_Total	46.90	29	4.475	0.831

PRE-TEST **37.66** → POST-TEST **46.90**

+9.24 point improvement
p < .001 (two-tailed)



FINDINGS

Paired t-tests were completed for statistical analysis. The mean difference between pre and post scores was -9.24 (pre minus post), with a standard error of 0.803 and a 95% confidence interval with a lower bound of -10.886.

The t-statistic was -11.512 with 28 degrees of freedom, and both the one-sided and two-sided p-values were < .001.

The result is highly statistically significant (p < .001, two-tailed). There is less than a 0.1% probability that a difference this large occurred by chance alone.

The intervention produced a statistically significant and practically meaningful improvement in scores. The results are robust and consistent across all indicators for HIV status and racial demographics.

< 0.1% probability the difference occurred by chance

Results robust across HIV status and racial demographics

CONCLUSION

Trauma can have significant impacts on health and even more so for persons living with HIV. Trauma-informed care practices have been recommended for persons who have experienced trauma.

A team-based training program regarding Trauma-Informed Care for persons who provide care to persons living with HIV can be helpful in increasing knowledge around trauma and increasing utilization of trauma-informed practices within care.

Follow-up research is recommended to assess patient data following a team-based training.

Follow-Up Inquiry

In December 2025 and February 2026, the investigator conducted follow-up inquiries, with many participants reporting the presentation had positively influenced their clinical practice and patient engagement, including feeling more patient and empathetic toward patients.

Paired Samples Test

	95% CI Upper	t	df	p (one-sided)	p (two-sided)
PRE - POST	-7.597	-11.512	28	<.001	<.001

p < .001
Highly statistically significant

29 participants completed both surveys

Physicians, PAs, NPs, behavioral health therapists, case managers, early intervention specialists, administrators

Acknowledgements

Thank you to Dr. Jason Young PhD for analytic analysis. Thank you to all participants. Special thanks to ACTHIV and the ChangeMakers program for support of this project.

ACTHIV ChangeMakers: Ablating Barriers to Anal Cancer Screening

Emily Yarman, MPAS, PA-C, AAHIVS

Community Health Network

BACKGROUND

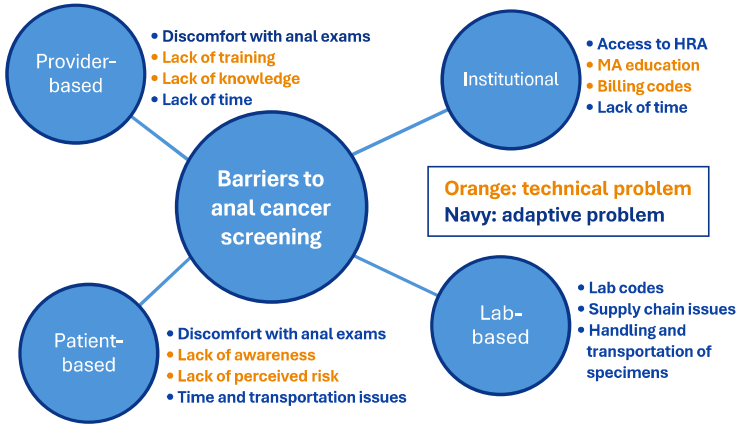
Anal cancer screening guidelines for PLWH were adopted in 2024[1]. Despite this, there remains a lack of uptake within my health network. Adaptive leadership models define problems as either "technical" or "adaptive." Kuluski et al.[2] define a technical problem as one that can be "managed with technological fixes or programmatic solutions" whereas adaptive challenges are those that have "many inputs and require changes in the ways of thinking and doing that cannot be solved by improving technical expertise alone." This framework may be useful to address barriers and increase the number of anal paps performed in at-risk HIV populations.

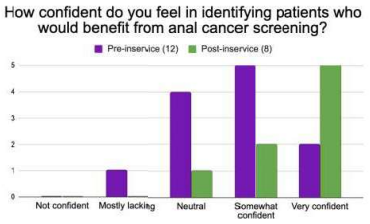
OBJECTIVE

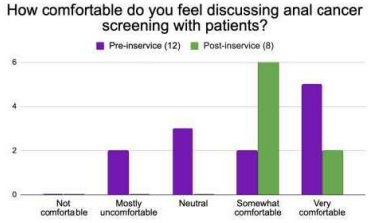
Identify and eliminate barriers to anal cancer screening to close this care gap within my health network.

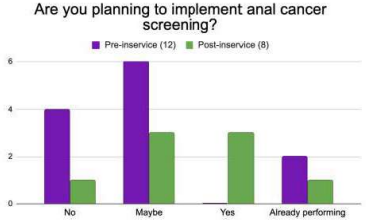
METHODS

Utilizing an adaptive leadership model, adaptive and technical problems were identified. Training and education were designed to address technical barriers: in-services for providers, training for MA staff, and educational discussions initiated with patients. For adaptive barriers, I collaborated with stakeholders to clarify adaptive challenges, including office staff, MAs, laboratory representatives, multiple specialties of clinicians, and patients.









RESULTS

After the in-service training, confidence in identifying patients to screen improved from 17% to 63%. Comfort level discussing anal cancer screening improved from 58% being at least somewhat comfortable to 100%. Only 17% of providers were already offering or planning to offer anal paps prior to the training, compared to 50% after the training. Adaptive barriers, including supply chain issues, specimen handling, pathology report accuracy, discomfort with anal exams, and availability of HRA were addressed through collaboration with stakeholders.

CONCLUSIONS

In any new process, barriers to implementation abound. An adaptive leadership framework is useful for identifying adaptive and technical barriers, which provides a starting point for problem-solving. Applying knowledge to the technical problem of provider discomfort with anal cancer screening notably improved confidence among these clinicians. Adaptive problems are, by their nature, difficult to define and solve. By engaging other stakeholders in the process, adaptive work can be shared and tackled more enthusiastically. As I continue my efforts to close the anal cancer screening care gap, adaptive leadership will aid in tackling emerging barriers.

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