Securing Your Oxygen Mask First!

How to Honor Unspoken Cultural Norms: *Continuing to Build Upon the Lessons Learned from the SPNS Enhancing Access to and Retention in Quality HIV/AIDS Care for Women of Color (WOC)*

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HIV/AIDS Bureau: Special Projects of National Significance (SPNS)

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HIV/AIDS Bureau Vision and Mission

Vision

Optimal HIV/AIDS care and treatment for all.

Mission

Provide leadership and resources to assure access to and retention in high quality, integrated care, and treatment services for vulnerable people living with HIV/AIDS and their families.

HIV/AIDS Bureau Priorities

- **NHAS 2020/PEPFAR 3.0** - Maximize HRSA HAB expertise and resources to operationalize NHAS 2020 and PEPFAR 3.0
- **Leadership** - Enhance and lead national and international HIV care and treatment through evidence-informed innovations, policy development, health workforce development, and program implementation
- **Partnerships** - Enhance and develop strategic domestic and international partnerships internally and externally
- **Integration** - Integrate HIV prevention, care, and treatment in an evolving healthcare environment
- **Data Utilization** - Use data from program reporting systems, surveillance, modeling, and other programs, as well as results from evaluation and special projects efforts to target, prioritize, and improve policies, programs, and service delivery
- **Operations** - Strengthen HAB administrative and programmatic processes through Bureau-wide knowledge management, innovation, and collaboration

Overview

- **Program Background of HRSA HAB Special Projects of National Significance (SPNS)**
- **Significance of the SPNS Initiative for Women of Color**
- **Lessons:**
  - Describe evidence-informed interventions and data requirements to explore the preexisting stigma and perception
  - Recognize how unspoken cultural norms can influence how this population accesses, understands, and seeks care
  - Identify ways to better tailor interventions to improve their patient's health outcomes that address their social coping mechanisms and mental health concerns that serve as both individual and structural barriers to treatment and care.

Ryan White HIV/AIDS Treatment Modernization Act of 2006: SPNS Authority and Purpose

TITLE VI—DEMONSTRATION AND TRAINING SEC. 601. DEMONSTRATION AND TRAINING.

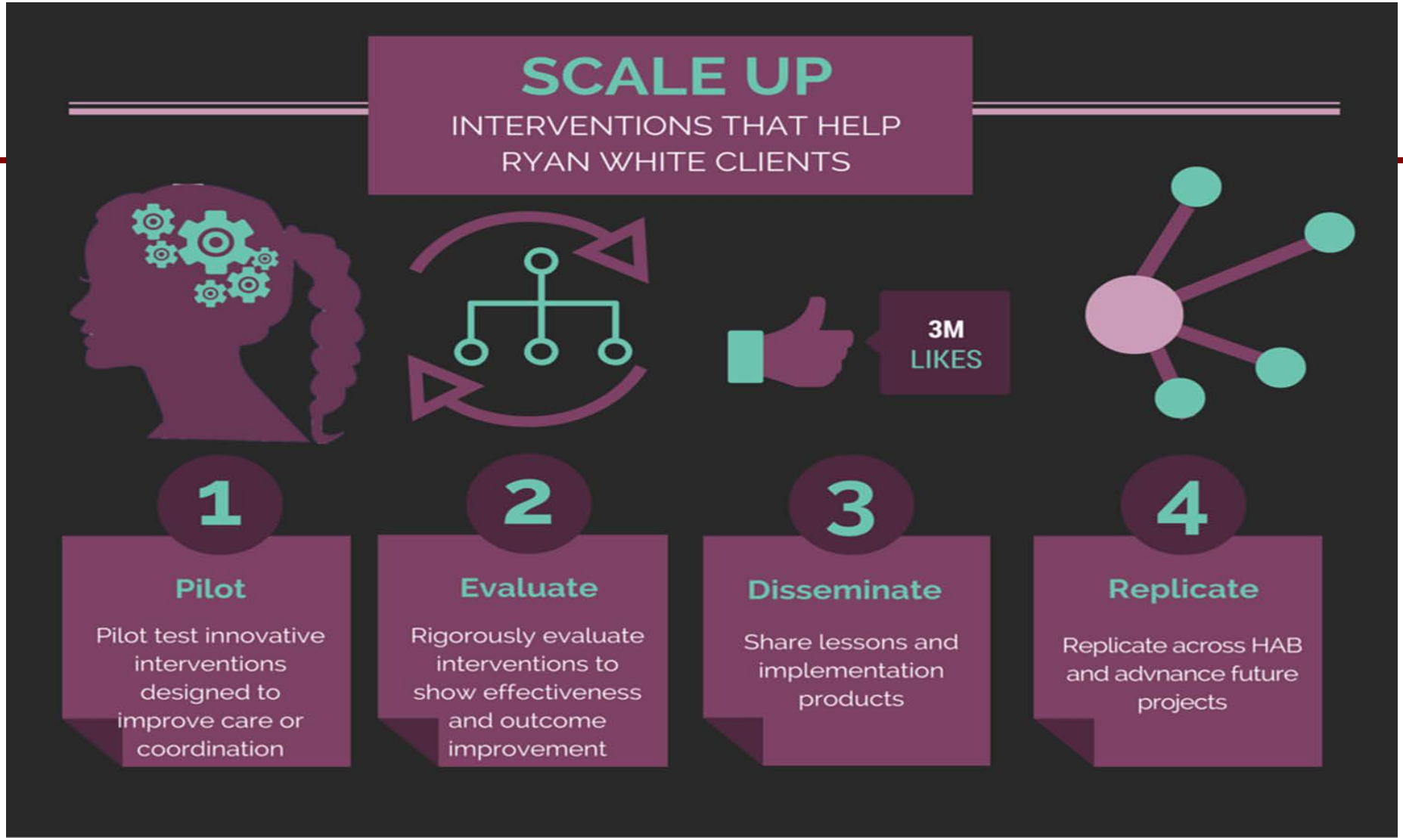
Subpart I of part F of title XXVI of the Public Health Service Act (42 U.S.C. 300ff–101 et seq.) is amended to read as follows:

"Subpart I—Special Projects of National Significance "SEC. 2691. SPECIAL PROJECTS OF NATIONAL SIGNIFICANCE. "(a) IN GENERAL.—Of the amount appropriated under each of parts A, B, C, and D for each fiscal year, the Secretary shall use the greater of $20,000,000 or an amount equal to 3 percent of such amount appropriated under each such part, but not to exceed $25,000,000, to administer special projects of national significance to—

"(1) quickly respond to emerging needs of individuals receiving assistance under this title; and

"(2) to fund special programs to develop a standard electronic client information data system to improve the ability of grantees under this title to report client-level data to the Secretary.

SPNS Mission



Women of Color: The Epidemiology

Why a SPNS Initiative for Women of Color? In 2004, HIV/AIDS was:

- The **fifth** leading cause of death among all U.S. women aged 35–44 and the **sixth** leading cause of death for those aged 25-34
- The **first** leading cause of death for African-American women aged 25-34 years and the **third** leading cause of death for those aged 35-44
- The **fourth** leading cause of death for Hispanic/Latina women aged 35-44 and the **seventh** leading cause for those aged 45-54

Source: CDC WISQARS 10 Leading Causes of Death, United States, 2004.

Women of Color: The Epidemiology

- By the end of 2012, CDC estimated that almost **284,500** women were living with HIV in the U.S. (23% of all Americans living with the virus)
- Women made up **19%** (8,328) of the estimated 44,073 new HIV infections in the U.S. in 2014, with **87%** acquiring the virus through heterosexual contact
- Among all women diagnosed with HIV in 2014, **62%** were African-American and **16%** were Hispanic/Latina
- In 2012, the Ryan White HIV/AIDS Program served 536,219 individual clients, of whom **262,247** (**49%**) were people of color, including **96,758** women **of color (18%)**

CDC. HIV Among Women Factsheet, March 2016; and data from the 2012 Ryan White Services Report (RSR)

SPNS Women of Color (WOC) Initiative

- 10 SPNS demonstration projects (5 urban, 5 rural)
- 921 women of color receiving HIV primary care and treatment services
- 18 month follow-up for two-thirds of the cohort
- Variety of access to care interventions (intensive case management, peer/promotoras, patient and nurse navigators, social media, transportation assistance, etc.)

Blank AE, Espino SL, Eastwood B, Matoff-Stepp S, & Xavier J. The HIV/AIDS Women of Color Initiative Improving Access to and Quality of Care for Women of Color. *Journal of Health Care for the Poor and Underserved.* February 2013; 24 (1): 15-26.

SPNS Women of Color Initiative Sociodemographics (n=921)

- African American: 67%, Hispanic/Latina: 27%
- Education: Less than HS: 41%, HS or greater: 59%
- Marital Status: Single: 61%, Married/partner: 16%
- Born in U.S.: 83%, outside of U.S: 17%
- Primary language spoken at home: English 87%, Spanish 13%
- Majority were low income and on public insurance

Eastwood EA, Fletcher J, Quinlivan EB, Verdecias N, Birnbaum JM, & Blank AE. Baseline Social Characteristics and Barriers to Care from Special Projects of National Significance Women of Color with HIV Study: A Comparison of Urban and Rural Women and Barriers to HIV Care. *AIDS Patient Care and STDs*, January 2015; 29 (Supplement 1): S4-S10.

Table 1. Summary of Grantee Sites and Interventions

Grantee Site	Model of Care	Project Name	Primary Intervention(s)
Care Resource Miami, FL	Clinic-based one-stop shop	I ACT for Women of Color (Intervention Assertive Community Treatment)	Coordination of medical and social care services, peer support, educational group sessions, individual adherence sessions, and multidisciplinary case review.
Ruth M. Rothstein CORE Center Chicago, IL	Clinic-based one-stop shop	Project WE CARE (Women Empowered to Connect and Remain Engaged in Care)	Peer patient navigation services and Healthy Relationships educational intervention.
JWCH Institute Inc. Los Angeles, CA	Co-located with and networked to providers	LODi (Ladies of Diversity)	Community health outreach workers and educators (primarily peer-based) performing intensive care coordination and peer support, and offering psychosocial services.
New North Citizens Council Springfield, MA	Community Development Agency facilitating access to providers within network	LEAPS (Latinas in Action Promoting Health)	Intensive, culturally based case management services.
SUNY Downstate Medical Center Brooklyn, NY	Network of clinic-based partners	POWER (Peer Outreach Worker Engagement & Retention)	Peer-based outreach, recruitment, and retention strategies and/or case management.

[i] Blank AE, Ryerson Espino SL, Eastwood B, et al. The HIV/AIDS women of color initiative improving access to and quality of care for women of color. *J Health Care Poor Underserved.* February 2013;24(1):15–26.

Table 1. Summary of Grantee Sites and Interventions (cont.)

Grantee Site	Model of Care	Project Name	Primary Intervention(s)
Health Services Center Hobson City, AL	Clinic-based providers within network	Project R-LINCS	Intensive case management services based on a strengths perspective and not limited by time or number of sessions.
Center for Human Services Bridgeton, NJ	Community organization linking to providers within network	LIFT (Latina Ladies Involved in Full Treatment)	Linkage services, linguistically and culturally based case management, translation services, and a behavior modification intervention.
Special Health Resources for Texas Longview, TX	Multifaceted institution with various clinic-based centers of care	Survival of the Fittest	Strengths-based individual case management sessions, group sessions, community education to reduce stigma, and survival stories to guide intervention/evaluation.
University of North Carolina Chapel Hill, NC	One-stop ID clinic within university hospital setting (capacity for ancillary support)	Guide to Healing	Linkage services, structural support with gas cards, parking vouchers and cell phones, a nurse acting as a guide to care, and a women's support group.
University of Texas Health Science Center San Antonio, TX	Partnerships with providers in network	HEART (HIV Entry Access and Retention in Treatment)	Outreach, medical coordination, patient navigation, and Healthy Relationships educational intervention.

SPNS Women of Color Findings

- 83% were retained in care (among 587 WOC in analysis sample)
- 73% were virally suppressed (among 357 WOC in analysis sample)
- Average age of women retained in HIV medical care was 40.9 and 41.9 for viral suppression
- Some factors associated with poor retention in care were indecision about seeking HIV medical care (AOR = 0.42) and having children under the age of 18 (AOR = 0.59)
- Some factors associated with lack of viral suppression were living with others (AOR = 0.58), current substance abuse (AOR = 0.38), and fair/poor health (AOR = 0.40)

Blank AE, Fletcher J, Verdecias N, Garcia I, Blackstock O, & Cunningham C. Factors associated with retention and viral suppression among a cohort of HIV+ women of color. *AIDS Patient Care and STDs*, January 2015; 29 (Supplement 1): S27-S35..

SPNS Women of Color Findings

The top five most frequently occurring barriers were:

- Needed more information about treatment
- Thought you might be judged
- Wanted to get back on track on your own
- Learn to live with it
- Feeling embarrassed/uncomfortable

Eastwood EA, Fletcher J, Quinlivan EB, Verdecias N, Birnbaum JM, & Blank AE. Baseline Social Characteristics and Barriers to Care from Special Projects of National Significance Women of Color with HIV Study: A Comparison of Urban and Rural Women and Barriers to HIV Care. *AIDS Patient Care and STDs*, January 2015; 29 (Supplement 1): S4-S10.

So Now What?

Exploring and Peeling the Onion to Get to the Core

http://www.buzzfeed.com/hnigatu/racial-microagressions-you-hear-on-a-daily-basis#.ijyV6eWOW, posted on Dec. 9, 2013

Microaggressions

- The term racial microaggressions was first proposed by psychiatrist Chester M. Pierce, MD, in the 1970s, but psychologists have significantly amplified the concept in recent years
- Definition: Microaggressions are common verbal, behavioral, and environmental indignities, whether intentional or unintentional, that communicate hostile or negative slights to marginalized groups. Perpetrators of microaggressions are often unaware that they engage in such interactions when they interact with minorities.

Sue DW, Capodilupo CM, Torino GC, Bucceri JM, Holder AMB, Nadal KL, & Esquilin M. Racial Microaggressions in Everyday Life – Implications for Clinical Practice. *American Psychologist*, May–June 2007; 62 (4): 271–286.

Cultural Competency and Cultural Humility: Yes there is a Difference…

- **Culture - One definition:** Culture is a set of learned beliefs, traditions, principles and guides for individual and collective behaviors that members of a particular group commonly share with each other
- **Cultural Competence – An operational definition**: the integration and transformation of knowledge about individuals and groups of people into specific standards, policies, practices, and attitudes used in appropriate cultural settings to increase the quality of services; thereby producing better outcomes

Davis K. Exploring the intersection between cultural competency and managed behavioral health care policy: Implications for state and county mental health agencies. Alexandria, VA: National Technical Assistance Center for State Mental Health Planning, 1997.

Potential Language and Cultural Barriers to Care

- Many of the SPNS WOC grantees found that the challenges that flow from poverty — unstable housing, homelessness and chaotic lives — often cause HIV-positive women of color to neglect or abandon their own health care
  - "If I'm hungry or don't have a home, I'm probably not going to be focused on taking care of myself physically"
    - Damiya Whitaker of the Center for Human Services

HIV/AIDS Bureau, Special Projects of National Significance Program. Implementation guide: enhancing access to HIV care for women of color. Rockville, MD: U.S. Department of Health and Human Services, Health Resources and Services Administration; 2014.

Potential Language and Cultural Barriers to Care

- **Communities of color often face obstacles to care, including the following:**
  - HIV stigma, particularly pervasive within some communities of color and especially among older generations and within churches and public institutions, makes it even more likely that WOC will delay or avoid care
  - Some Hispanics/Latinas may avoid seeking testing, counseling, or treatment because of immigration status or fear of discrimination

HIV/AIDS Bureau, Special Projects of National Significance Program. Implementation Guide: Enhancing access to HIV care for women of color. Rockville, MD: U.S. Department of Health and Human Services, Health Resources and Services Administration; 2014.

Potential Language and Cultural Barriers to Care

- Black immigrant women from the Caribbean and Africa may have internalized attitudes of blame around their home countries' high rate of HIV and long histories in the global pandemic. These feelings can keep them from disclosing their status and seeking care
- Within some parts of the African-American community (particularly in the South), deep levels of distrust for the medical community exist. This profound level of distrust, related in part to the lingering impact of the Tuskegee experiments and other discriminatory practices often leads to a lack of engagement in care
- A lack of culturally competent care also can present additional barriers, as some medical personnel may be unfamiliar with different cultural norms

HIV/AIDS Bureau, Special Projects of National Significance Program. Implementation Guide: Enhancing access to HIV care for women of color. Rockville, MD: U.S. Department of Health and Human Services, Health Resources and Services Administration; 2014.

Potential Language and Cultural Barriers to Care

- Making faulty assumptions about a community can lead to lack of preparedness to provide culturally competent care with linguistic or cultural support
- Some examples of attitudes and values that are interrelated with culture which Providers should be aware include:
  - Accepted roles of men and women
  - Value of traditional medicine versus Western medicine
  - Favorite and forbidden foods
  - Manner of dress
  - Body language, particularly whether touching or proximity is permitted in specific situations

HIV/AIDS Bureau, Special Projects of National Significance Program. Implementation Guide: Enhancing access to HIV care for women of color. Rockville, MD: U.S. Department of Health and Human Services, Health Resources and Services Administration; 2014.

Potential Language and Cultural Barriers to Care

- The power of STIGMA: SPNS WOC Grantees reported that women of color living with HIV had been rejected in church, forced to use plastic utensils, ostracized by neighbors, and accused of being prostitutes

- This kind of fear can drive people underground and contribute to delayed entry into care

Potential Solutions: Language and Cultural Barriers to Care

- Providers need to become more aware of inherent bias they may unknowingly bring to their practice and impart on their patients
- Cultural humility can be implemented to avoid 'patronizing and pandering' to patients
- Organizations may wish to incorporate mental health care into their service offerings (if they don't offer these services already) to assist women in addressing any internalized shame, depression, and other mental health issues
- Beyond analyzing demographic data and surveillance information, SPNS WOC grantees reported that reaching out and obtaining input from patients and staff before starting any kind of program development is a critical step — perhaps even the most important step — in creating a successful intervention

HIV/AIDS Bureau, Special Projects of National Significance Program. Implementation Guide: Enhancing access to HIV care for women of color. Rockville, MD: U.S. Department of Health and Human Services, Health Resources and Services Administration; 2014.

The National CLAS Standards

(**C**ulturally and **L**inguistically **A**ppropriate **S**ervices)

- Published in 2000 to improve health care quality and advance health equity by establishing a framework for organizations to serve the nation's increasingly diverse communities
- **Principal Standard**: to provide effective, equitable, understandable and respectful quality care and services that are responsive to diverse cultural health beliefs and practices, preferred languages, health literacy and other communication needs

Office of Minority Health. The National Standards for Culturally and Linguistically Appropriate Services in Health and Health Care. http://minorityhealth.hhs.gov/omh/browse.aspx?lvl=2&lvlid=53

The National CLAS Standards

(Culturally and Linguistically Appropriate Services)

Expanded Standards	National CLAS Standards 2000	National CLAS Standards 2013
Culture	Defined in terms of racial, ethnic and linguistic groups	Defined in terms of racial, ethnic and linguistic groups, as well as geographical, religious and spiritual, biological and sociological characteristics
Audience	Health care organizations	Health and health care organizations
Health	Definition of health was implicit	Explicit definition of health to include physical, mental, social and spiritual well-being
Recipients	Patients and consumers	Individuals and groups

Office of Minority Health. The National Standards for Culturally and Linguistically Appropriate Services in Health and Health Care. file:///I:/HAB/2016%20HRSA%20Symposium/NationalCLASStandardsFactSheet.pdf

Where to Find More Information about SPNS

http://hab.hrsa.gov/abouthab/partfspns.html

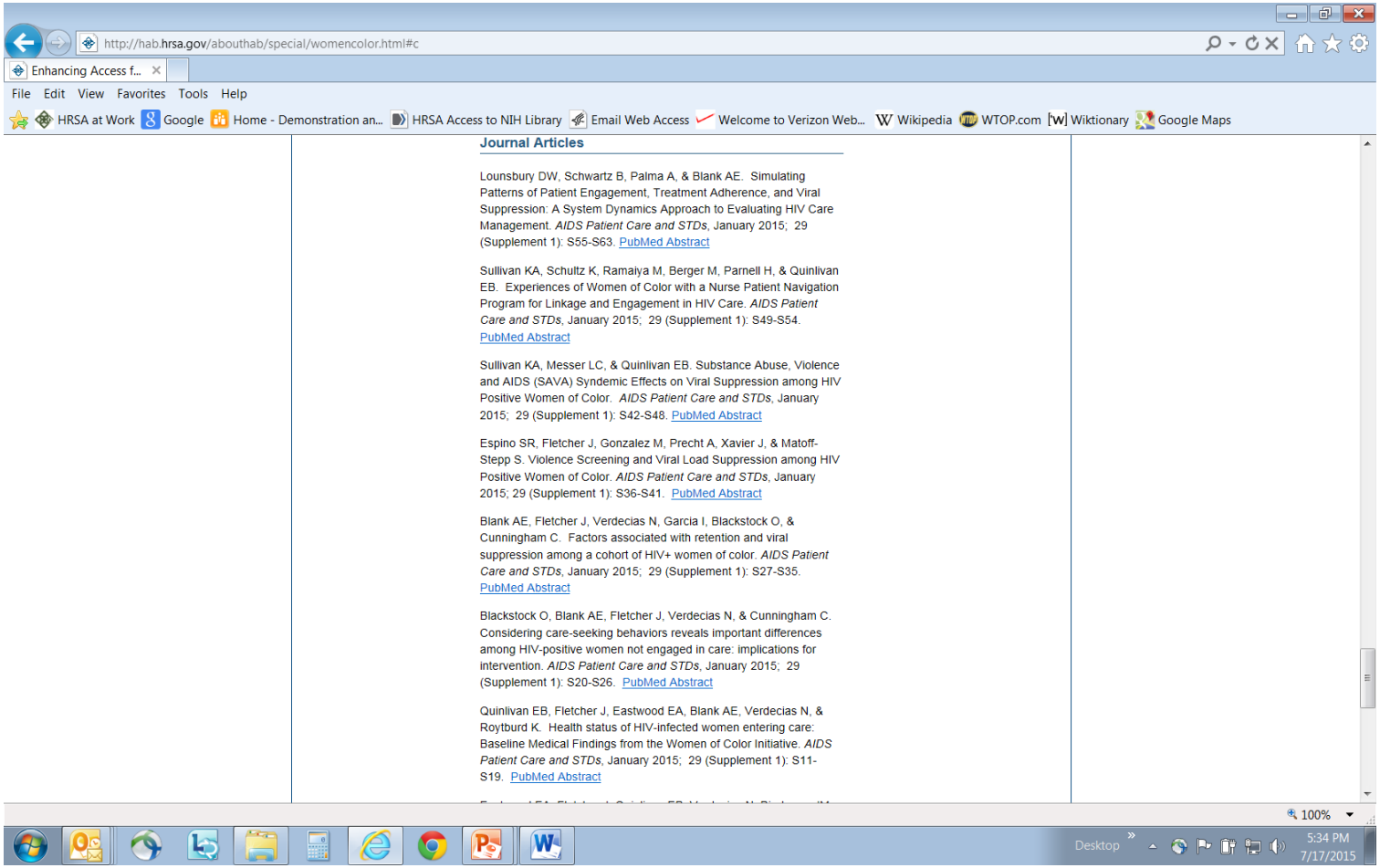
Where to Find SPNS Journal Articles

http://hab.hrsa.gov/abouthab/special/previousinitiatives.html

Where to Find SPNS Journal Articles

http://hab.hrsa.gov/abouthab/special/womencolor.html

Where to Find SPNS Journal Articles



http://hab.hrsa.gov/abouthab/special/womencolor.html#c

Thank You! Questions?

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