# Lessons learned on integrating a CHW-led research project on cervical cancer screening in 2 safety net clinics









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#### Introduction

- We describe a Community Health Worker (CHW) and clinical partnership to improve cervical cancer screening among Hispanic/Latinas and Haitian women.
- In the US:
  - African American women die twice as frequently from cervical cancer than non-Hispanic Whites
  - Hispanic women have the highest incidence
  - These minority populations are less likely to get
     Pap smears in safety net institutions

#### Meet CHW Valentine César

"As a CHW, I have put in place some strategies to help facilitate higher screenings at the clinic:

1. Reduce waiting time in the clinic's lobby by overcoming language and culture barrier encountered by the community

- 2. Increase the **community's access** to the health care system
- 3. Reinforce the **community's trust** in the health care system
- 4. Improve the community's health education"

Video here.

#### Meet CHW Orieta Fontán

"Ideas that I procured while working as a CHW in the Jackson Clinic to implement the study:

- 1. Importance of **previous background information** for the clinical health staff that will be involved in the research study.
- 2. Coordinate a strategy that allows the development of this study without interfering in the dynamics of the clinic.
- 3. Ensure resources that **guarantee the privacy and safety** of the participants of this scientific study."

Video here.

#### **Cervical Cancer and Minorities**

#### Incidence:

 African Americans and Hispanics higher than NHW (9.6 vs. 10.9 vs. 7.9 per 100,000)

#### Mortality

 African Americans higher than Hispanics and NHW (4.2 vs. 2.9 vs. 2.2 per 100,000)

#### Miami

- Mortality: African Americans highest
- Incidence: Haitian women highest in Little Haiti

### **Barriers to Screening**

- Patient-Level
  - Financial, Modesty, Discomfort, Transportation
- Provider-Level
  - Competing interests, Cost (Time and \$)
- System-Level
  - Limited resources, limited staffing, lack of linkage between clinic – referral center

### Reasons for Less Screening

- Among Minorities:
  - older age, lack of insurance, less education, less income, and no usual source of care
  - modesty, fatalism, and having a male provider
- Among Haitian women in Miami:
  - lack of health insurance, lack of money to pay for screenings, language, immigration status, knowledge, fear and modesty associated with obtaining a Pap smear, fear of knowing a cancer diagnosis, and socio-cultural beliefs

### **How to Improve Screening Rates**

- Safety net clinic providers encounter barriers to providing Pap smears.
  - uninsured, immigrants, no usual source of care
- Must overcome individual, provider, and system level barriers.
- HPV self-sampling, where patients self-collect a vaginal/cervical sample, may increase screening rates in these clinical settings: at Jackson Health System and the Center for Haitian Studies.

# Role of HPV Self-Sampling-1

 HPV self-sampling: women self-collect vaginal/cervical sample for testing by HPV DNA or RNA PCR.



# Role of HPV Self-Sampling-2

- Nearly as sensitive as physician collected samples
- Demonstrated to be acceptable in clinical and community settings
- Less costly than traditional screening methods

### **Study Objectives**

- CHWs as intervention to offer HPV selfsampling to Haitian and Hispanic safety net clinic patients
- Assess acceptability of HPV self-sampling method
- Assess feasibility and acceptability of HPV self-sampling among clinic staff

### **Participants**

- Recruitment by convenience sampling
- Study period: May 2013 February 2014
- Eligibility Criteria
  - Ages 30 65 years
- Exclusion Criteria
  - Had Pap smear in prior 3 years
  - Pregnant
  - Hysterectomy
  - Actively Menstruating



#### Site 1: JHS

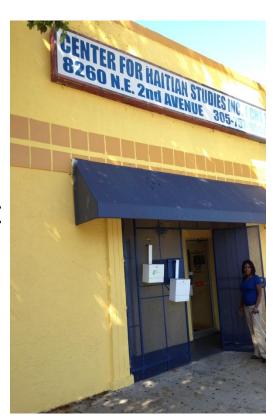
- CHW Orieta Fontán
   Latina patient population
- Jackson Health System:
   Ambulatory Care Center West 3B Clinic –
   General Medicine
  - Resident clinic for internal medicine residency program
  - Payment is determined by financial assessment (discount provided based on poverty level)
  - Cost of care varies (\$0 \$150 per PCP visit) but includes a Pap smear





#### Site 2: CHS

- CHW Valentine César, Haitian patient population
- Center for Haitian Studies (CHS)
  - Community Health Center in Little
     Haiti
  - Funding through grants and patient contributions
  - Pap smear cost additional to PCP visit (approximately \$150 for GYN consultation plus Lab fee)



#### **Procedures**

- Community Health Worker (CHW)-led intervention
- Two CHW partners (one Cuban and other Haitian)
- Received two-week training:
  - Core competencies
  - Cancer education and outreach
  - Cervical cancer and HPV
  - Cancer clinical trials
  - Completed CITI Program certification
- Then tasked with recruiting a total of 180 women into the study

#### Recruitment

- Cuban CHW recruited at JHS, Haitian at CHS
- Approached women waiting to see provider in waiting room
- Provided brief description of study
- Assessed for eligibility
- Administered language-specific Informed Consent and intake survey forms
- Provided a \$20 grocery store gift card

#### **CHW Provided Education**

- Received brief education with a flipchart
  - Lots of visuals
  - Covered topics such as:
    - Normal female anatomy
    - Cervical cancer progression and risk factors
    - Described HPV self-sampler



# **Participant Screening Choice**

Participants were offered: HPV self-sampling, no HPV self-sampling, or talk with provider first

- 1. If HPV self-sampler selected, received sampler and instructions
- 2. If no HPV self-sampler selected, requested permission to review medical record to check if Pap smear performed

### **Option 1: HPV Self-Sampler**

- Administered 12-item survey assessing attitudes towards and acceptability of HPV self-sampling and Pap smear
  - Survey translated and back translated in Spanish and Haitian Creole
- Sample collection occurred in clinic bathroom with CHW outside to answer questions
- Swab placed in liquid medium and discarded
- Tested for HPV by PCR
- If HPV detected, CHW navigated participant to Pap smear

# **Option 2: No HPV Self-Sampler**

Chart reviewed
 approximately 5 months
 after recruitment to check
 if Pap smear had been
 performed



### **Clinic Staff Survey**

- All clinic staff informed at baseline of study
- At end of study, survey emailed or given on paper to clinic staff
- Consists of 9-items
  - Assesses attitudes towards cervical cancer screening and HPV self-sampling
  - Items adapted from CDC survey assessing provider acceptability of rapid HIV testing

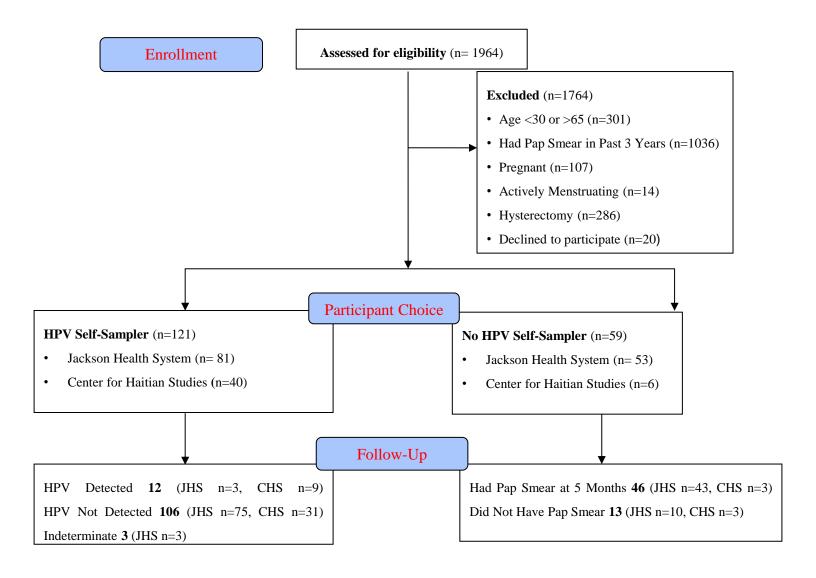
#### **Measures-1**

- Acceptability among participants:
  - Perceptions of the HPV self-sampler with regard to the Pap smear
  - Provider offering screening or not
  - Ease of use
  - Willingness to use the sampler again
  - Recommending to a friend or family member
  - Comfort of use in the clinic setting
  - Experience of pain with sampler use
  - Preference of sampler versus Pap smear
  - Perception of using the sampler correctly

#### **Measures-2**

- Acceptability: Answer to survey item identifying provider willingness to incorporate HPV selfsampling into clinical practice
- Remaining items: Assess secondary outcomes
  - provider perception of the importance of cervical cancer screening
  - concern regarding inadequate screening among their patients
  - barriers to performing cervical cancer screening
  - awareness of and ability to discuss HPV self-sampling with patients

#### Results



### **Patient Sample Characteristics**

- Mean Age 52.7 (SD 7.6)
- Majority Latina (74%) from JHS
- Uninsured and/or no Medicaid (97%)
- 74% low income (< \$15,000/year)
- Married (38%)
- Immigrants (97%)
  - Years since entering USA: Mean 15.5 years (SD 13)
- JHS (Latinas mostly): more US citizens, more education, higher income, more years since entering US among immigrants than Haitians

### **CHW Valentine says:**

"I have helped to make these women feel welcome and at ease. Some days were there was no patient waiting to be seen at the general medicine department, I would stay and help with the pregnant women with their paper work.

Or sometimes I would just help them to calm down by talking to them, holding or playing with a baby. They can become very irritable for waiting too long or simply because they are tired."

### **CHW Orieta says:**

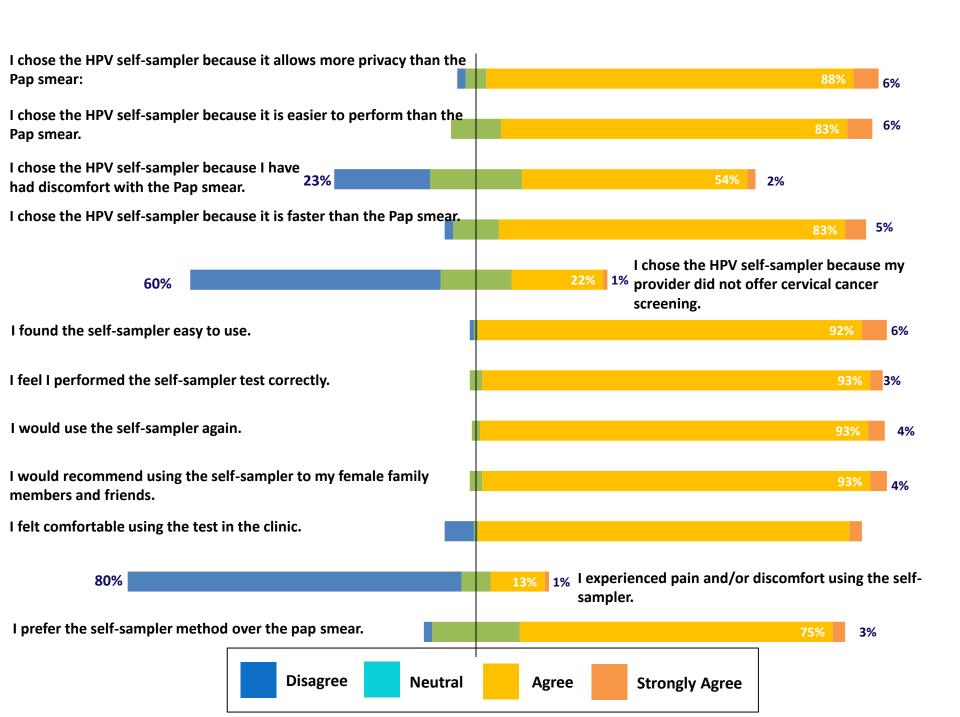
"Out of the 81 Latinas who chose to self-sample, more than 50% of them were over the age of fifty. My observation was that they preferred the privacy and the minimal pain or discomfort. For patients, privacy in this clinic may have been a greater concern since this is a teaching hospital. Some patients were embarrassed to have a pap smear done by two people in the room, the student and the instructor. Many of the participants expressed that they had not had a Pap smear done in over ten years. They stated they would not done the check-up if it wasn't for the HPV self – sampler.

The participation of a CHW was important throughout the entire process at the clinic. As a Latina myself, I was able to identify with them."

#### **Results: Acceptability among Patients**

Primary outcomes: 180 recruited

- 121 (67%) Selected HPV self-sampler
- 59 (33%) Selected not to use self-sampler
- Over 90% agree that HPV self-sampling is:
  - More private than Pap smear
  - Easy to perform, faster
  - Feel they performed the test correctly
  - Would use the self-sampler again
  - Would recommend it to a friend or family member



### **HPV Self-Sampler Test Results**

- HPV Detected: 12 samples (10%)
- HPV Not Detected: 106 samples (88%)
- Indeterminate: 3 samples (2%)

### **Had Pap Smear**

- Among 59 who did not use HPV self-sampler
  - 46 (78%) had Pap smear at 5-months postrecruitment
  - Median days until Pap smear: 60
  - Pap smear results:
    - 36 (78%) Normal
    - 7 (15%) ASCUS
    - 1 (2%) LSIL
    - 1 (2%) HPV test only
    - 1 (2%) Missing result in medical record

# Clinic Staff Acceptability Survey

- Web-Survey invitation emailed or paper survey given to 178 clinic staff
- 39 completed surveys (Response Rate of 22%)
- Characteristics:
  - Worked at JHS (87%)
  - Resident physicians (51%)



#### Results

- Staff agreed that:
  - Would be willing to incorporate HPV selfsampling into clinical practice: 80%
  - Cervical cancer screening important: 100%
  - Concerned patients not adequately screened: 69%
  - Difficult to perform Pap smear due to time constraints: 66%

### **CHW Valentine says:**

"I was very interested in helping the patients waiting for consultation in the lobby. As a small community health center, CHS has a limited staff, and assisting a new patient in filing out papers is very time consuming, particularly if you are asking for information about their financial status. Some patients may spend one or two hours waiting for someone to help them. In the meantime they may miss their turn to be seen by the doctor. As a Haitian I already know how to approach them and help them overcome their language barrier.

Every time I am assessing a patient for the HPV self sampler I took the opportunity to help them with their paper work. Also, the women feel more comfortable answering some personal questions when they are talking to me. Most of the time, the center has only one physician and sometimes this physician needs a translator in the consultation room."

### **CHW Orieta says:**

"I was able to identify with the views and concerns of the patients and assist in the clinic dynamics so that it might be welcoming to the Latina patients. For example, I often helped call out patient names to be seen when clinic staff did not know the correct pronunciation for a Hispanic name. Latinas felt comfortable talking to me in their language and about their experiences because they knew I would have an understanding of our culture."

#### **Conclusions**

- HPV self-sampler very acceptable to patients and clinic staff.
- Integration of CHW-led screening program into clinics using HPV self-sampling was feasible.
- Similar results to previous studies of acceptability; this screening strategy may help overcome barriers to cervical cancer screening in these settings.