

# Everybody Loves a Good Story: *Using digital media to capture & share patient stories*

Jane Fox, MPH, Boston University School of Public Health

Nicole Chisolm, MPH, AIDS Arms, Inc.

Janell Tryon, MPH, Asian & Pacific Islander Wellness Center

# Disclosures

## Presenter(s)

Jane Fox, MPH, Nicole Chisolm, MPH and Janell Tryon, MPH have no financial interest to disclose.

This continuing education activity is managed and accredited by Professional Education Services Group in cooperation with HSRA and LRG. PESG, HSRA, LRG and all accrediting organizations do not support or endorse any product or service mentioned in this activity.

PESG, HRSA, and LRG staff has no financial interest to disclose.

# Learning Objectives

At the end of this presentation participants will be able to:

- describe 2 types of digital storytelling used;
- discuss some of the successes and challenges in producing the digital media products presented; and
- describe basic elements needed to design their own digital media product.

# Why Tell the Story?

***Do the one thing you think you cannot do.  
Fail at it. Try again. Do better the second time.  
The only people who never tumble are  
those who never mount the high wire.  
This is your moment. Own it.***

*Oprah Winfrey*

# Building a Medical Home SPNS Initiative

- To engage homeless/unstably housed persons living with HIV who have persistent mental illness and/or substance use disorders in HIV and behavioral health care and to assist in obtaining housing
- 9 sites across the U.S.

# Intervention Model

- Building a medical home for HIV-positive homeless population
  - Housing partnerships
  - Behavioral health partnerships
  - Systems integration
- Use of network navigators for systems integration and care coordination

# Stories vs. Research

- Even though storytelling is an increasingly popular research method, it doesn't have to be!
  - **Qualitative Research:** is used to better understand reasons, opinions, and experiences of study participants. Usually multiples narratives are recruited, documented, and analyzed.
  - **Storytelling:** is an age-old attempt for humans to communicate their human experiences, share histories and traditions, teach, entertain, inspire, and be heard.

# The Assignment & Product

## Year four of a five-year initiative:

- Design and produce a patient story using digital media to be presented in June, 2016 at the initiative grantee meeting.

## Two storytelling modalities:

- AIDS Arms, Inc. created a **narrated photo story**
- APIWC interviewed multiple clients for the first episode of the second season of the agency's **podcast**



# Narrated Photo Stories | AIDS ARMS

*Health, Hope & Recovery is a program of AIDS Arms, Inc. located in Dallas, TX.- Intensive care coordination intervention to link and retain individuals who are HIV+, multiply diagnosed and homeless in a medical home.*

- Narrated photo stories combine recorded client testimonials with digital photo stories.
- Focus areas: Emergency housing and intensive care coordination

# Podcast | A&PI Wellness Center

*The HHOME Program - Providing intensive mobile medical care, case management, & peer navigation to multiply-diagnosed folks living with HIV, experiencing chronic homelessness*

*Community exCHANGE - “People Living with...” is the second season of the APIWC podcast. This season focuses on the intersectionality of stigma and the lived experiences of those living with HIV, racism, transphobia, mental health issues, substance use, and more. Audience includes: providers, clients, friends, family, and community members.*

# Approaching & Recruiting

## AIDS ARMS

- Recruitment was conducted by Care Coordinators
- \$25 Wal-Mart Gift card (and bus pass if needed)
- Full disclosure of intent
  - Client advocacy
  - Donor recruitment for emergency housing
- Signed Release Form Required

## A&PI Wellness Center

- The three clients involved in episodes were recruited by Social Worker, Peer, & Evaluator
- \$50 compensation
- Full disclosure of intent
  - Client advocacy
  - Community Engagement
- Signed Release of Audio/Photo Form Required

# Process of Building the Story *at AIDS ARMS*

## Record

- Develop specific questions
- Obtain signed release form
- Conduct client interview

## Transcribe & Storyboard

- Transcribe audio
- Outline transcription
- Create storyboard

## Edit & Produce

- Enhance quality
- Identify relevant photos
- Anonymize audio and photos
- Compile photos and overlay audio recording

# Process of Building the Episode *at A&PIWC*

## RECRUIT & RECORD

- 1) Interview 3 clients
- 2) Interview 1 provider
- 3) Record 4 interviews

## STORYBOARD

- 1) Listen to interviews
- 2) Draw out themes
- 3) Organize Flow of episode

## PRODUCE

- 1) Train staff on editing software
- 2) (Spend weeks) EDITING
- 3) Voila!

# Health, Hope, & Recovery

AIDS Arms Video:

<http://medheart.cahpp.org/sites/default/files/AIDS-Arms-Client-Story.mp4>

# “People living with...”

A&PI Wellness Center podcast excerpt

[http://medheart.cahpp.org/sites/default/files/clips\\_mixdown.mp3](http://medheart.cahpp.org/sites/default/files/clips_mixdown.mp3)

# Successes and Challenges: Across Sites

## Successes

- Overwhelming client support
- Promoted peer advocacy
- Donor support
- Client empowerment

## Challenges

- Transcription and editing
- Software/equipment & audio quality
- Multiple editors

## THINGS to CONSIDER

### *for clients*

HIV disclosure and stigma

Trauma // Reliving Trauma

### *for staff*

Bandwidth

Effect on community

Power of addressing community-wide issues



# Uses & Dissemination *for AIDS ARMS*

## USES

1. Demonstrate effectiveness of the emergency housing program, from the client perspective
2. Supplement quantitative outcomes of the emergency housing program
3. Solicit donor support

## DISSEMINATION

- Conferences
- Agency Staff
- Key Stakeholders (partner agencies & boards)

# Uses & Dissemination *for A&PIWC*

## USES

1. Expand podcast audience to include more clients and community members
2. Further humanize our clients // highlight their creativity
3. Solicit community support by supplementing clinical data

## DISSEMINATION

- Conferences
- SoundCloud | iTunes
- APIWC Training Platform
- Stakeholder Meetings

# Healing & Empowerment

Many sites found that storytelling had the ability to:

- ✓ offer the client perspective, regarding the Medical Home SPNS Initiatives, to providers and the broader community
- ✓ deepen knowledge within agencies about the work of these particular programs
- ✓ heal and empower those clients who told their unique stories
  - One client involved in the podcast was motivated to disclose her HIV status to her partner after years of secrecy and shame.
  - She shared that she finally felt empowered to do so and unburdened and free immediately following her disclosure.

# Continuing the Narrative...

Asian & Pacific Islander Wellness Center is now in its second season of the Community exCHANGE podcast, where staff speak with clients, providers, scholars, and community members.

Season 2—“People living with...” —is addressing the lived experience of the intersectionality of stigma. Upcoming episodes:

- 2) Stigma & the PIC: How the prison system interrupts community, reinforces stigma
- 3) Mental Health: Speaking up and out...How to talk about mental health from within
- 4) Blurring the Line...Problematizing the CBO structure/Client-oriented all around—Use HHOME as a model
- 5) The Community Factor...How is belonging to a bigger picture protective for staff and clients? Incorporating Social Justice/Advocacy/Academia for staff and clients

The Podcast can be found by searching for “Community exCHANGE podcast “ or at <https://itunes.apple.com/us/podcast/podcast-community-exchange/id1118513989?mt=2>

# Other Examples

Changing Lives through Good Oral Health:

<http://cahpp.org/resources/digital-story-changing-lives-good-oral-health/>

# Inspired?

- Start with your message
  - Who is your audience?
  - Find your story
  - Find your venue
  - Develop the story
  - Share the story again and again and...
- Resources:
    - <http://meyerfoundation.org/sites/default/files/files/SWT-Whitepaper-FINAL.pdf>
    - <http://www.fundraising123.org/files/NFG-Storytelling-Guide.pdf>
    - <http://www.nten.org/article/15-ways-harness-power-nonprofit-storytelling-advocacy/>

# Contact us...

Jane Fox, MPH

PI/PD | Boston University School of Public Health

E: [janefox@bu.edu](mailto:janefox@bu.edu) P: 617.638.1937

Nicole S. Chisolm, MPH

Program Evaluation Director | AIDS Arms, Inc.

E: [nicole.chisolm@aidsarms.org](mailto:nicole.chisolm@aidsarms.org) P: 214.521.5191

Janell Tryon, MPH

Evaluator | Asian & Pacific Islander Wellness Center

E: [janell@apiwellness.org](mailto:janell@apiwellness.org) P: 415.292.3420 x334