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# The Ethics and Practice of Digital Storytelling as a Methodology for Community-Based Participatory Research in Public Health

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*Et al.*

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# The Ethics and Practice of Digital Storytelling as a Methodology for Community-Based Participatory Research in Public Health

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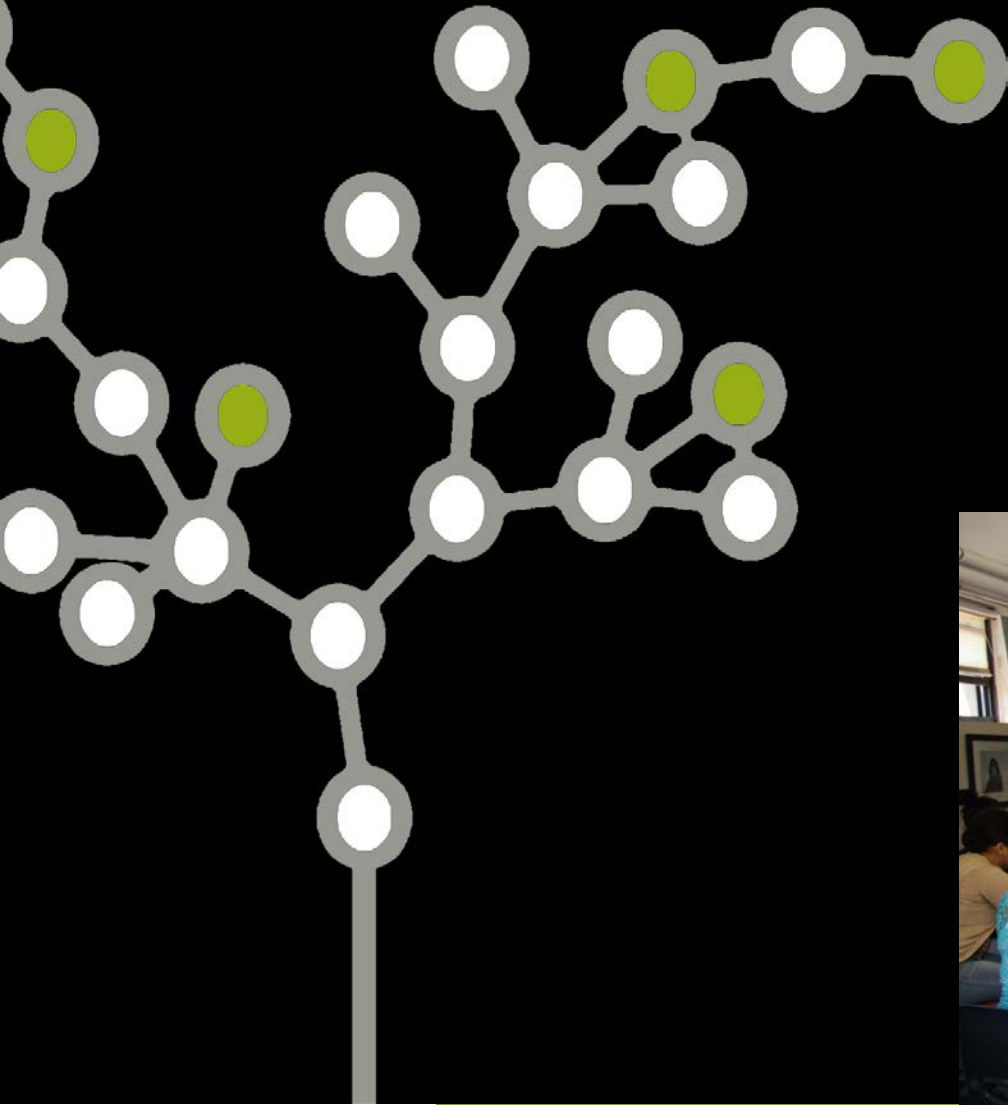
*Review of Digital Storytelling Methods*

Aline Gubrium

An Ethics Framework
for Digital Storytelling as a Multi-Purposed Public Health Method

Orientation → Prompts → Script writing → Story circle → Voiceover → Rough edit → Final edit → Workshop airing → Public screening

*View Story*

Review of Digital Storytelling Methods

# A Situated Practice of Ethics: Addressing Challenges

Aline Gubrium

An Ethics Framework
for Digital Storytelling as a Multi-Purposed Public Health Method

# Ethical Issue 1: Fuzzy Boundaries

- Confusion between where priorities lie (research vs. intervention/practice vs. advocacy) can lead to very different implementation approaches.



A Situated Practice of Ethics

# Ethical Issue 2: Recruitment and Consent to Participate

- There is a fine balance between protecting individuals who are in the midst of trauma from further harm and patronizing potential participants through exclusion. Those featured in the digital story may be unaware or upset about their inclusion.



A Situated Practice of Ethics

# Ethical Issue 3: Power of Shaping

• Facilitators may help "shape" the narrative to produce stories that will resonate with audiences, inadvertently imposing their own agendas. Sharing power often means losing control over messaging.



A Situated Practice of Ethics

# Ethical Issue 4: Representation and Harm

- Digital stories can misrepresent communities and/or reify stereotypes. Exposing illegal or illicit activity might endanger storytellers or subjects.



A Situated Practice of Ethics

# Ethical Issue 5: Confidentiality

- Stories are sometimes so distinct that it is impossible to guarantee confidentiality. Often participants want to be credited by name for their contributions. The visual and sharable nature of digital stories must also be considered.

A Situated Practice of Ethics

# Ethical Issue 6: Release of Materials

• Needs to be negotiated on an ongoing basis. Some stories reveal very personal issues that can make participants vulnerable to stigma and discrimination. Storytellers might want to change their stories or to change their minds later on.



A Situated Practice of Ethics

Ethical engagement in public health research and practice is an ongoing, iterative, and complex process. Rather than positioning ethics as an introductory component to a project—a one-off occasion of gaining consent—ethics must be understood as a process that involves ongoing dialogue among all stakeholders about how best to design and implement an ethically responsible project" (Gubrium, Hill & Flicker, 2014).

"Mastering this form of respect—proper consent forms, arranging informed consent, filling forms and completing ethics applications—is only the first step. Putting our words into action, this is the real content of respect" (Menzies, 2012).



A Situated Practice of Ethics

|  | Situation | Issues | Example | Ethical Practice |
|---|---|---|---|---|
| **Fuzzy Boundaries** | Nexus of public health intervention/practice, research and advocacy | Confusion between where priorities lie, affects implementation | Research, training, strategic communications components, multiple partners involved. | Partners need agreement about specific goals, objectives, policies and procedures |
| **Recruitment and Consent to Participate** | Sponsors want to recruit diverse or targeted participants to share their stories.<br><br>Consent to participate is sometimes indirect. | Balance between protecting individuals in trauma and patronizing them through exclusion<br><br>Those featured in story may be unaware or upset | Working within CBO constraints for recruitment and participation.<br><br>Paris's inclusion in the project and her story.<br><br>Ongoing participation of storytellers. | Transparency with participants about benefits and risks of participation.<br><br>Provide safety and supports.<br><br>Consent from all featured. |
| **Power of Shaping** | Personal stories are encouraged: Tension between process and products | "Shaping" of stories to resonate with audiences. Shared power = less control over messaging. | Shaping of presentations and materials according to venue (community vs. academic) | Reflexive attention—cultural humility is key. Storyteller wellbeing should be at the center of a project. |

|  | Situation | Issues | Example | Ethical Practice |
|---|---|---|---|---|
| **Representation and Harm** | Participant tells a story that makes us uncomfortable or expose themselves to harm through the process | Digital stories can misrepresent communities or reify stereotypes. Exposed activities may endanger storytellers or subjects. | Paris's story exposes her ex.<br><br>Storytellers at public screenings. | Storyteller wellbeing at the center of a project. Supports in place. Dialogue with storytellers and/or audiences to challenge messages. |
| **Confidentiality** | May not always be possible or appropriate. | Distinct stories difficult to guarantee confidentiality. Participants want to be credited by name. | (IRB) Human Subjects' review<br><br>Clashing agendas for the project | When possible, credit storytellers for their work by name (or chosen pseudonym), to maintain their ownership. |
| **Release of Materials** | Consent to participate in a workshop is not the same as release of materials (dissemination) | An ongoing process. Stories can make participants more vulnerable. Stories may change their minds over time. | Website construction. Ongoing use of stories. Negotiating partner and storyteller perspectives. | Provide options for story release (where, why, how, by whom). Case-by-case basis for release. Iterative and ongoing. |

**Silence Speaks**

**Digital Storytelling for Healing, Transformation, and Justice**

# Digital Storyteller's Bill of Rights

## The Workshop

- The right to know from the outset *why* a workshop is being carried out.
- The right to assistance in deciding whether you are ready to produce a digital story.
- The right to understand what is involved in the process of producing a digital story.
- The right to know who might view your finished story, after the digital storytelling workshop.
- The right to decide for yourself whether or not to participate in a workshop.
- The right to ask questions at any stage of the workshop, before, during, or after.
- The right to ask for teaching instructions to be repeated or made clearer.
- The right to skilled emotional support, if your experience of making a story is emotionally challenging.
- The right to tell your story in the way you want, within the limits of the workshop.
- The right to decide whether or not to reveal private or personal information to fellow participants and instructors, at the workshop.
- The right to advice about whether revealing your identity or other personal details about your life, in your story, may place you at risk of harm.
- The right to leave information and/or photographs that identify you or others, out of your final story.
- The right to reject story feedback (about words and images) if it is not useful or offered in a spirit of respect/support.
- The right to decide what language to use in telling/creating your story.
- The right to be respected and supported by capable workshop facilitators.
- The right to a written consent form, if your story will be shared publicly, including a signed copy for your records.
- The right to know what contact and support you can expect after the workshop

## Sharing Your Digital Story After The Workshop

- The right to decide with project partners how your story will be shared after the workshop.
- The right to view and retain a copy of your story before it is shared publicly in any way.
- The right to know who is likely to screen your story and for what purposes.
- The right to know who is likely to watch or read your story and when (e.g. rough timeframe).
- The right to advice about how the process of publically sharing your story may be difficult.
- The right to emotional support if you are present when your story is shown in public.
- The right to demand that no one should be able to sell your story for profit.
- The right to know if any money will be made from your story being shared (e.g. to support not-for-profit human rights work).
- The right to withdraw your consent for the use of your story at any time.
- The right to information about the limits of withdrawing consent for your story to be shared, if it has already been circulated online or on CD, DVD, etc.

# Ethics Questions

- How Will You Protect and Enhance Storyteller Well-Being?

- How will You Handle Consent Issues?

- How Will You Support Storyteller Benefits / Ownership?

- How Will You Make Sure Your Project is Locally Relevant?

- How Will You Weave Ethics Discussions Throughout Your Work?

- How Will You Ensure Ethical Distribution of Stories?

Applying the Ethics Framework

# Stakeholder Engagement and Ethical Planning for Digital Storytelling:
# The MOCHA Moving Forward Project

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UMass Amherst School of Public Health and Sciences

March 3, 2017

# Project Overview and Aims

- **Using a community-based participatory research approach:**

  – Examine the bio-psychosocial determinants of stress among older, African-American men in Springfield, MA.

  – Assess the effectiveness of the MOCHA program to decrease stress among older, African-American men in Springfield;

  – Assess the comparative effectiveness of a narrative-based version of the MOCHA program to decrease stress among OAAM.


MOCHA
Men of Color Health Awareness

# Introduction and Background

- **Older, AA men experience high levels of stress.**
  - Structural inequalities
  - Social networks
  - Gender identity
- **Men of Color Health Awareness (MOCHA) Program**
  - 12-weeks, 3-days/week (2 gym/workout, 1 discussion-based group meeting)
  - 15-20 men per cohort, ages 35-65
  - Holistic approach to health: physical, mental, social, spiritual (e.g. black masculinities)
- **Research Collaboration (2016-2021)**
  - UMass-Amherst SPH, Department of Health Promotion and Policy Investigators
  - City of Springfield Department of Health and Human Services (MOCHA Steering Committee)
  - Study Sites: YMCA, UMass-Springfield Center

# Why do African-Americans have flattened cortisol profiles, higher levels, and cortisol dysfunction?

- ¾ black adults reported experiencing racially based daily discrimination (e.g., disrespectful treatment, receiving poorer services)

- Higher rates of chronic stress observed in minority populations across all socioeconomic levels.

- Discrimination during adolescence continued to produce dysfunctional cortisol rhythms by age 32 (Northwestern University 20-year study)

- Positive racial identity can help

- Internalized racism intensified stress

# Stress and Digital Storytelling

- **Why Stress?**
  - Identified as community priority
  - Allows for investigation of other community priorities and interests
  - Contributes to poor mental health and chronic disease outcomes
  - Experience, expertise, and interest among researchers

- **Why Storytelling?**
  - Storytelling akin to historical and daily practices of narrative and cultural production for many AA communities.
  - Nuanced, complex, and contextualized communication
  - Data and intervention
  - Counter-narratives: education and advocacy

- **How DST is being used in the project?**
  - Led by Gubrium (Co-I), Lowe (GRA), and Scott (MOCHA Outreach and Community-Building Coordinator)
  - 4 digital storytelling workshops of 10 men each (n=40)
  - December-May

# Fuzzy Boundaries in the DST Process

- **OUR GOAL**: To gather data on factors related to stress and produce stories that could be used as part of an intervention to decrease stress.

- **OUR PROMISE**: Participants are free to share, discuss, and create the story that they most want to tell, prioritizing their control and autonomy over their stories.

- How do we square these two goals?

# Writing Prompts

## Write about a moment when…

- You learned what it meant to be a man

- You felt like you had to "man-up" or someone expected you to "be a man"

- A meaningful relationship changed the course of your life

- You should have been stressed but you weren't

- You felt seen or included, or felt overlooked or invisible

- You kept quiet or you spoke up

- You felt the need to react or not react to an act of everyday racism

- You couldn't control something or someone, or you felt in control

- You felt proud to be a man, a man of color, or proud to be yourself

# Fuzzy Boundaries Around Consent

- DST is both data and intervention.

- Participants are screened for PTSD prior to taking the pre-test or attending the workshop. This is a precaution to protect potential participants from a group-based storytelling process that could trigger previous trauma.

- ETHICAL CONCERN: Denying participants the right to participate in an intervention aimed at reducing stress because their stress levels are too high.

**Participant Recruitment**

# Sample Story

# Questions

1. What was it like for you leading or participating in DST workshops?
2. What lessons have you learned from engaging stakeholders in DST projects?
3. What advice regarding ethical considerations do you have for others who will conduct DST as part of their research?
4. When or in what situations have you found ethical issues surrounding DST especially challenging?
5. What drawbacks or cautions do you have about DST?
6. What challenges, barriers, or concerns have you confronted related to stakeholder engagement for DST?

# Digital Storytelling as Health Promotion and Data:
## Ethical considerations from a peer mentor-based project to address perinatal substance use disorder in a rural community

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# Ethical Considerations

- Population

- Setting

- Confidentiality

- Researcher

Thank you!