

*Lessons Learned and
Challenges to Face:
HIV Research, Fully Engaged*

AVAC Webinar

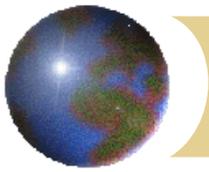
HIV Vaccine Awareness Day

Thursday, May 17, 2018

Mark Hubbard

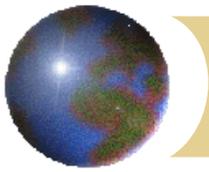
HVTN: SGC, ETWG , & AMP

TAPWA: Education Liaison



Lessons Learned: *Why stakeholder engagement?*

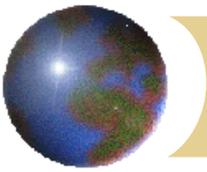
- ✦ It's the right thing to do
(“research done with us, not to us!”)
- ✦ The result is better research –
higher productivity, more useful results,
less risk of futility, more success



Lessons Learned:

Foundational Values

- ❖ Stakeholders impacted by research must be meaningfully involved...
(individuals, groups, institutions)
- ❖ ...in all research aspects... (agenda, trial design, education and recruiting, informed consent, and dissemination of results)
- ❖ ...across the entire timeline – from before trial design through after results are out

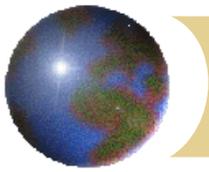


Lessons learned:

Resources must be allocated

- ⊕ Dedicated staff support
- ⊕ Materials & Equipment
- ⊕ Travel, meals, etc

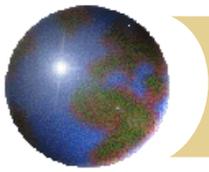




Lessons Learned:

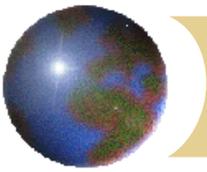
Mixed Methods

- ❖ Community Advisory Boards / Groups are a long-established and valuable system
- ❖ Alone or in isolation, however, they are not enough
- ❖ Other groups, methods and forms of consultation must also be used

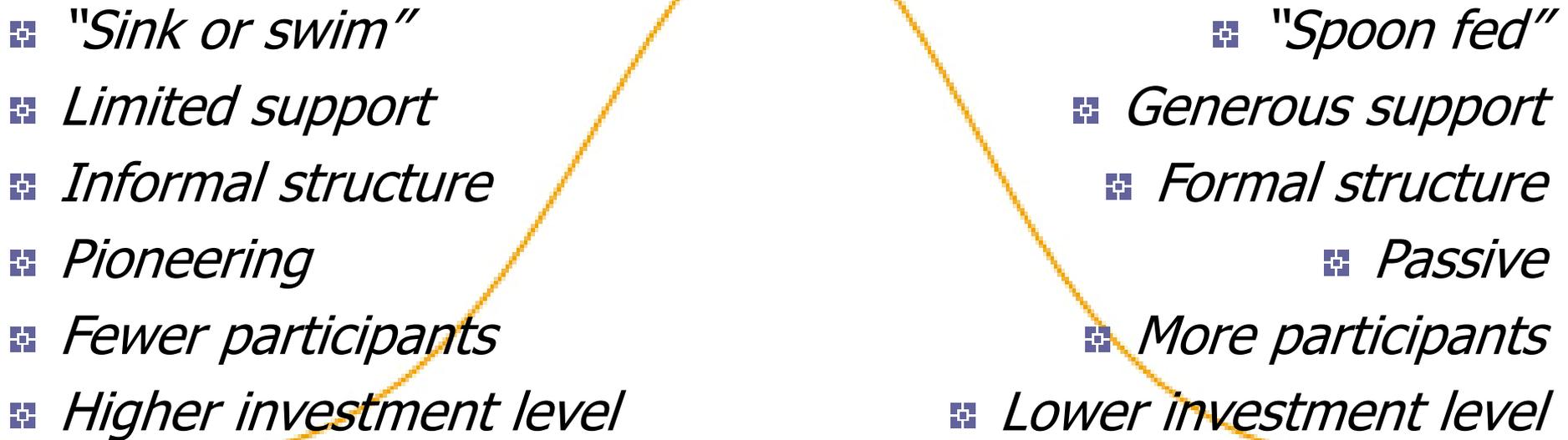


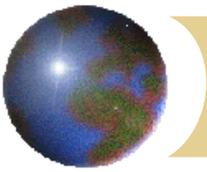
Where we are now: *Good Participatory Practice (GPP)*

- ⊕ GPP is the “Standard of Engagement”
- ⊕ GPP is a comprehensive structural framework built on longstanding values, synthesizing decades of collective experience and expertise

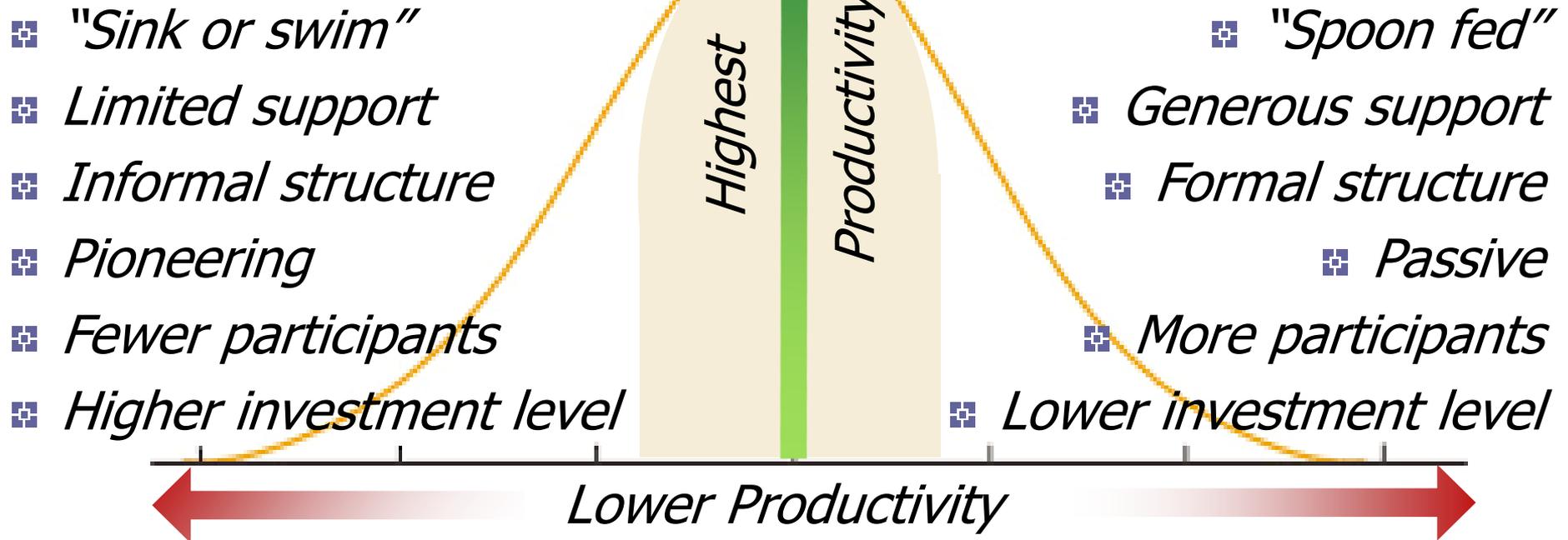


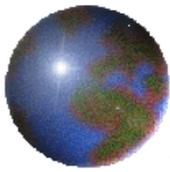
Challenges to Face: Engagement Spectrum





Challenges to Face: Engagement Spectrum





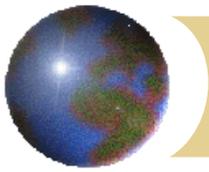
Challenges to Face: Silos & Bridges

HIV.gov | HIV BASICS | FEDERAL RESPONSE | DIGITAL TOOLS | EVENTS | BLOG | POSITIVE SPIRIT

HOME | EVENTS | Awareness Days

AWARENESS DAYS

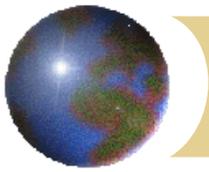
 February 7 National Black HIV/AIDS Awareness Day #NBHAAD	 March 10 National Women and Girls HIV/AIDS Awareness Day #NWGHAAD	 March 20 National Native HIV/AIDS Awareness Day #NNHAAD	 April 10 National Youth HIV & AIDS Awareness Day #NYHAAD
 April 18 National Transgender HIV Testing Day #TransHIV	 May 18 HIV Vaccine Awareness Day #HVAD	 May 19 National Asian & Pacific Islander HIV/AIDS Awareness Day #APIMay19	 June 5 HIV Long-Term Survivors Day #HLTSAD2017
 June 27 National HIV Testing Day #HIVTestingDay	 September 18 National HIV/AIDS and Aging Awareness Day #NHAAD	 September 27 National Gay Men's HIV/AIDS Awareness Day #NGMHAAD	 October 15 National Latinx AIDS Awareness Day #NLAAD
 December 1 World AIDS Day #WAD2017			



Challenges to Face: Silos & Bridges

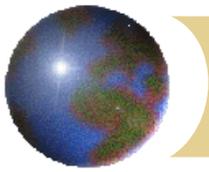
The image shows a grid of social media posts for various HIV/AIDS awareness days. The central post, which is circled in red, is for HIV Vaccine Awareness Day (May 18th) with the hashtag #HVAD. Other posts include National Transgender HIV Testing Day (April 18th), National Asian Pacific Islander HIV/AIDS Awareness Day (May 19th), and National Aging Awareness Day. The posts are arranged in a grid with overlapping edges, and the central post is highlighted with a red circle.

Event Name	Date	Hashtag
National Transgender HIV Testing Day	April 18	#NTHTD
HIV Vaccine Awareness Day	May 18	#HVAD
National Asian Pacific Islander HIV/AIDS Awareness Day	May 19	#APIMay19
National Aging Awareness Day		



Challenges to Face: Silos & Bridges

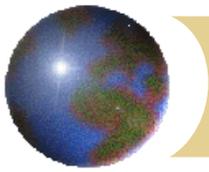
- ✚ Is vaccine research in 2018 just about vaccines? (what about PrEP? antibodies? treatment? cure?)
- ✚ What other awareness days should be on the calendar?



Challenges to Face:

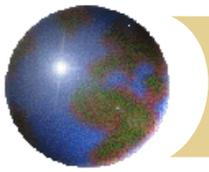
Silos & Bridges

- ⊕ How do we build mutually beneficial relationships among everyone involved?
 - ⊞ Other networks,* institutions, priorities
 - ⊞ Other research stakeholder groups especially “inside” vs. “outside”
 - ⊞ Community organizations / stakeholders not traditionally engaged in research advocacy



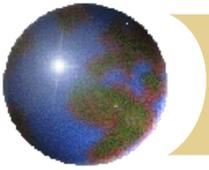
Challenges to Face: Silos & Bridges

- ✚ Getting to know and understand each other and our histories (stakeholder engagement cultures) is important to strategic collaboration.



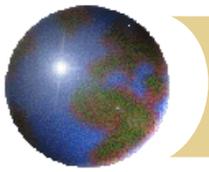
Challenges to Face: *Silos & Bridges*

- ✦ Is our stakeholder engagement broad and thorough enough?
- ✦ What are we doing to recruit the next generation of advocates?
- ✦ How do we integrate the newbie, the naive, the outsider, the challenger?



Challenges to Face: *Focus*

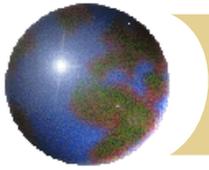
- ✚ The research agenda changes over time; stakeholder engagement focus and strategy must adapt.



Current Key Issue #1a:

What is the Standard of Prevention?

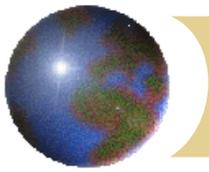
- ⊕ How should the standard of prevention within a trial compare to that in the community at large?
- ⊕ **Is it our role to follow or to lead?**



Current Key Issue #1b:

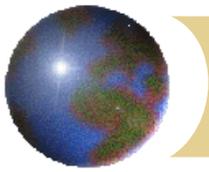
What is the Standard of Prevention?

- ✚ Is Truvada as PrEP part of the standard of prevention for vaccine trials?
Where? When? How?



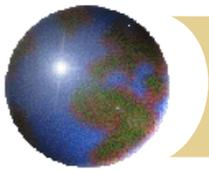
Current Key Issue #2: Prevention Efficacy Trial Design

- ❖ As the effectiveness of the (combined methods) standard of prevention rises, the risk of futility increases.
- ❖ How do we conduct HIV prevention efficacy trials that can and will answer the efficacy question?



Current Key Issue #2: Prevention Efficacy Trial Design

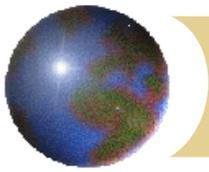
- ✚ Can exclusion criteria, investigator discretion, or recruitment messaging be ethically used to reduce the number of persons using PrEP or other biomedical prevention products in vaccine trials?



Current Key Issue #2:

Prevention Efficacy Trial Design

- ⊕ What alternate trial designs can be used to combat futility?
- ⊕ Who do we need to engage to accelerate alternate trial design development?
 - ⊠ Research entities, experts
 - ⊠ Regulatory agencies (governments)
 - ⊠ End users / participants
 - ⊠ Civil society at large



Thank You.

Mark Hubbard

mark@hivsci.org

615-715-1517