

Public Engagement and Involvement in Health Research: How well are we doing? Views from the global north *and* the **global south.**

Presenter: Dr Anastasia Koch

- Director, Eh!woza
- Junior Research Fellow, MMRU, IDM, UCT

Presenter: Nabeel Petersen

- Director, **Interfer**
- Co-founder, **Pivot Collective**

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GLOBAL
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NETWORK**
Enabling research by sharing knowledge

mesh
— community engagement network —

Outline.

1. **Global Health Context:** Anastasia/Nabeel
2. **Eh!woza background:** Anastasia
3. **Pivot Collective/Interfer Background:** Nabeel
4. **Successes/Challenges around research-led engagement:** Anastasia
5. **Engagement outside of institution:** Nabeel
6. **Discussion**

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Global South – South African Context.

1. **Internet:** 59.3%

53%  rely on mobile connection; 9.5% home access [StatsSA]

2. **Secondary School Completion:** 30,7% [StatsSA]

3. **Unemployment:** 30.1% (pre-Covid19) [StatsSA]

4. **TB:** incidence of 520 per 100 000 [WHO]

5. **HIV:** prevalence of 20.4% - 424 per 100 000 [UNAIDS]

6. **COVID:** 159 333 total, 2.79 % case fatality [SA Dep Health]

7. **Trust in science:** 74% trust advice from doctors + nurses; 54% believe science in SA is beneficial [Wellcome Global Science Monitor]

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EH!WOZA: AN EXAMPLE

LEARNING | CONSOLIDATION

1. INTENSIVE ENGAGEMENT LEARNER PRODUCED DOCCIES



ENGAGE HIGH SCHOOL LEARNERS WITH RELEVANT BIOMEDICAL RESEARCH AND PROVIDE THE NECESSARY SKILLS AND PLATFORM FOR LEARNERS TO PRODUCE DOCUMENTARIES ABOUT THE PERSONAL AND SOCIAL IMPACT OF TB/HIV.

2. INTENSIVE ENGAGEMENT DR-TB/MUSICIANS/MSF COLLAB



CONNECT YOUNG DR-TB SURVIVORS WITH LOCAL MUSICIANS TO ENCOURAGE THE SHARING OF EXPERIENCES AROUND DR-TB THROUGH STORY TELLING THAT INSPIRES THE DEVELOPMENT OF POETRY, MUSIC AND MUSIC VIDEOS.

3. BROADER DISSEMINATION SCHOOLS EDUCATION PROJECT



USE MEDIA PRODUCED IN (1) AND (2) TO ENGAGE A MORE EXTENSIVE AUDIENCE OF HIGH SCHOOL YOUTH TO STIMULATE DIALOGUE AND GENERATE ACTIVISM AROUND TB/HIV AND THE SOCIAL DETERMINANTS OF HEALTH.



EXPANSION | SHARING OF KNOWLEDGE



TRACKING CHANGE | IMPACT ASSESSMENT

HIGH-LEVEL QUALITATIVE



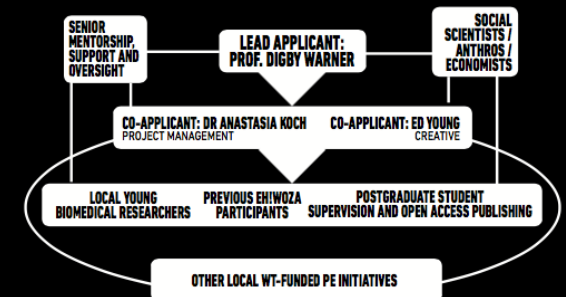
THE COLLABORATION HAS PRODUCED THREE PAPERS, TWO PHD CANDIDATES, TWO GRANTS (WT208083/Z/17/2, SA-NRF116273) OVER THREE YEARS. THIS WILL BE EXPANDED TO PRODUCE HIGH-IMPACT QUALITATIVE ASSESSMENT AROUND HEALTH PUBLIC ENGAGEMENT.

INNOVATIVE QUANTITATIVE



MODELS WILL INITIALLY BE DEVELOPED TO BE LOCALLY RELEVANT, COULD BE ADAPTED TO OTHER LOW-MIDDLE INCOME SETTINGS. THIS IS CURRENTLY BEING PILOTTED IN A CORPORATE RESPONSIBILITY COLLABORATION WITH [RBB ECONOMICS](#).

- Newly independent NPO:
- Incubated within academic institute (IDM)
 - Wellcome multi-year discretionary award – local platform for PE



CAPACITY | SUSTAINABILITY

With thanks to funders/partners/support.



SAMRC/NHLS/UCT Molecular Mycobacteriology Research Unit



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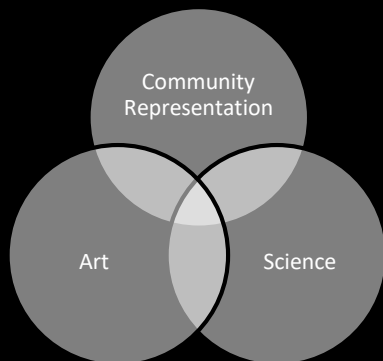
Inclusive Research & Engagement.

Participation.

Storytelling.

Engagement.

Methods Exploration & Dev.



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(Egalitarian) Collaboration in Public Health & Public Engagement.

Collab & Inclusive Knowledge Production.

Collab Knowledge Translation.

De-Colonized Research.



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Research-led engagement: Successes/Challenges.

- Scholarly work:
 - Peer-reviewed papers
 - Formal lectures
 - Postdoc in PE (in progress)
- Capacity development:
 - Young biomedical researchers (PhD, postdocs)
 - “Formalise” PE
- Change in culture is slow
- PE not always valued/resourced as much as biomedicine
- Administrative bureaucracy
- Tick boxing

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Engagement from outside of institution.

Challenges:

- Uni-directional Engagement
- Tickboxing
- Engagement/Research as distinct processes
- “us” vs “them”, i.e. mirrors traditional Development thought
- As external: Limited power to influence; Max power to explore/challenge/advocate
- Meaningful Engagement requires multi- / diverse-skillsets
- Engagement is not Once-off

Requires Improvement:

- Participation & Inclusion of beneficiaries and varied stakeholders
- Inclusion & Participation (from design to evaluation)
- Innovation. Innovation. Innovation...
- Engagement and research as continuous didactic process
- Greater immersion in knowledge co-production & co-translation
- De-colonization or -structuring of imagined static processes