

## AIDS 2022: What communities should take away from the science?

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# **AIDS 2022: WHAT COMMUNITIES SHOULD TAKE AWAY FROM THE SCIENCE?**


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**APHA & DTHF ENGAGEMENT FORUM**

29 August 2022



# **CONFLICT OF INTEREST & DISCLOSURE**

I have no conflict of interest.

Information on the slides are from the AIDS  
2022 website.

*“Success only comes to those who dare to attempt”*

*Mallika*

*Together we can be significant*

# ACKNOWLEDGEMENTS

- IAS mentorship programme
- Audience
- Community Stakeholders
- Study Participants
- Advocates
- Researchers, Regulatory and Ethical Groups

## GOAL

- To share knowledge and jointly encourage collective action through informed decision making guided by science.
- Promote community science & partnerships in the research agenda.
- Advocate the use of effective local communication tools and resources in the science landscape.

# OUTLINE

- What is Science?
- Key messages from AIDS 2022 for the community stakeholders
- Strategies for evolution of community partnerships in science



# WHY SCIENCE IS CALLED SCIENCE?

- Original term from the Latin word Scientia which meant knowledge, a knowing, expertness, or experience.
- Late 14th century, science meant, in English, collective knowledge.
- Consistently carried the meaning of being a socially embedded activity: people seeking, systematizing and sharing knowledge.
- Science is a systematic enterprise that builds and organizes knowledge in the form of testable explanations and predictions about the universe.

# MESSAGES

- Acknowledge the elements (earth, water, fire and air) and the contributions of our ancestors in all research.
- Human rights and ethics is key in all science.
- Decolonize research and messages and advocate local cultural input.
- Botswana reached 95-95-95 targets despite resources limitations. Learn lessons

# MESSAGES

- Reduce costs of CAB LA and promote local vaccine manufacturing capacity and transfer of IP.
- Explain COVID-19 vaccines for disease prevention vs virus acquisition and why no current vaccines for HIV prevention or treatment.
- Promote self testing as data shows that with education and access to kits, diseases may be prevented, treated and managed.

# MESSAGES

- Person and Human centered framework to be part of research studies.
- Social science issues around addressing stigma, uptake of biomedical technologies, equity and equality.
- Structural drivers such as GBV and poverty continue to impact HIV, TB, COVID-19 and other diseases.

# MESSAGES

- Post trial access of effective biomedical interventions needs to be part of the protocol at the concept stage.
  - Access to participants and population who will benefit from the interventions
- Delivery mechanisms to suit community needs, be cost effective and sustainable e.g. Lessons from oral PrEP uptake.

# MESSAGES

- Community stakeholders play a critical role in ensuring populations who may benefit from interventions are part of the research.
- Example: pregnant and breastfeeding populations needs to be part of trials as they may acquire HIV in some settings but are underrepresented.
- <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC9178651/>

# MESSAGES

- Science needs our active partnership as stakeholders
- Implementation and action needed as adequate data exists on impact of structural and social factors on global health.
- Stakeholders to be partners in science outcomes and outputs

# STRATEGIES FOR COMMUNITY PARTNERSHIPS AND SCIENCE

- Study participants and community members to be the voices of science e.g. peer educators programmes.
- Advocates and messengers of health to include youth, elderly, traditional leaders, traditional healers who are our effective influencers in the community.
- Communication science to review role of social media platforms that share facts and respond to concerns and feedback.




# STRATEGIES FOR COMMUNITY PARTNERSHIPS AND SCIENCE

- Communication science to review role of social media platforms that share facts and respond to concerns and feedback.
- Optimize social media to raise awareness and share facts.

Example: SHERPA Study in SA, WHO 5 minutes talks, DOH messages

# SHERPA MESSAGE




13 July 2022

**Inviting all Sisonke participants  
who have not had a Pfizer boost**

**Convert your Sisonke participation  
into additional protection**

**Enrol in the SHERPA (Sisonke 4) study  
to access a  
Moderna mRNA-1273 booster vaccine**

 To link with a SHERPA study site  
<https://redcap.link/sherpa>  
or visit your nearest site.

[www.samrc.ac.za/media-release/samrc-launches-study-evaluate-effectiveness-moderna-booster](http://www.samrc.ac.za/media-release/samrc-launches-study-evaluate-effectiveness-moderna-booster)

# SHERPA SITES



Inviting all Sisonke participants who have not had a Pfizer boost

14 July 2022

Convert your Sisonke participation into additional protection

Enrol in the SHERPA (Sisonke 4) study to access a Moderna mRNA-1273 booster vaccine



To link with a SHERPA study site <https://redcap.link/sherpa> or visit your nearest site.

#### Gauteng

• Aurum - Pretoria	012 844 0144
• Aurum - Tembisa Clinic	087 135 1645
• MeCRU (Medunsa)	012 521 3052
• PHRU Soweto Kiptown CRS	063 654 5581
• Setshaba Research Centre CRS	012 799 2422
• Clinical HIV RU (CHRU), Helen Joseph Hosp	081 869 1120
• UBUNTU - Lenasia	063 684 3973
• UBUNTU - Krugersdorp	063 684 3973
• Wits RHI Sandukani	064 648 8638

#### KwaZulu Natal

• CAPRISA eThekweni	031 655 0613
• CAPRISA Vulindlela	031 655 0689
• Qhakaza Mbokodo, Ladysmith	036 631 2372
• SAMRC Botha's Hill CRS	031 777 1585
• SAMRC Chatsworth CRS	031 401 4150
• SAMRC Ispingo	031 902 7894
• SAMRC Tongaat CRS	032 944 2208
• SAMRC Verulam	032 533 4345

#### Western Cape

• DTHE Emaundleni CRS	021 650 5869
• DTHE Masiphumelele CRS	021 785 5454
• FAM-CRU - Tygerberg Hospital	021 938 4157
• Task EDEN	044 873 3395
• TASK Central	021 917 1226

#### Eastern Cape

• Nelson Mandela Academic RU	047 150 0012
• PHOENIX Pharma (Pty) Ltd	041 373 3832
• Synergy Biomed Research Institute	043 722 2306

#### North West

• Aurum - Klerksdorp	087 135 1594
• Aurum - Rustenburg	087 135 1550

#### Limpopo

• Ndlovu RC, Elandsdoorn	013 983 8759
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#### Mpumalanga

• MERC Middelburg	013 243 5697
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#### Free State

• Joshua Research CRS	051 412 8160
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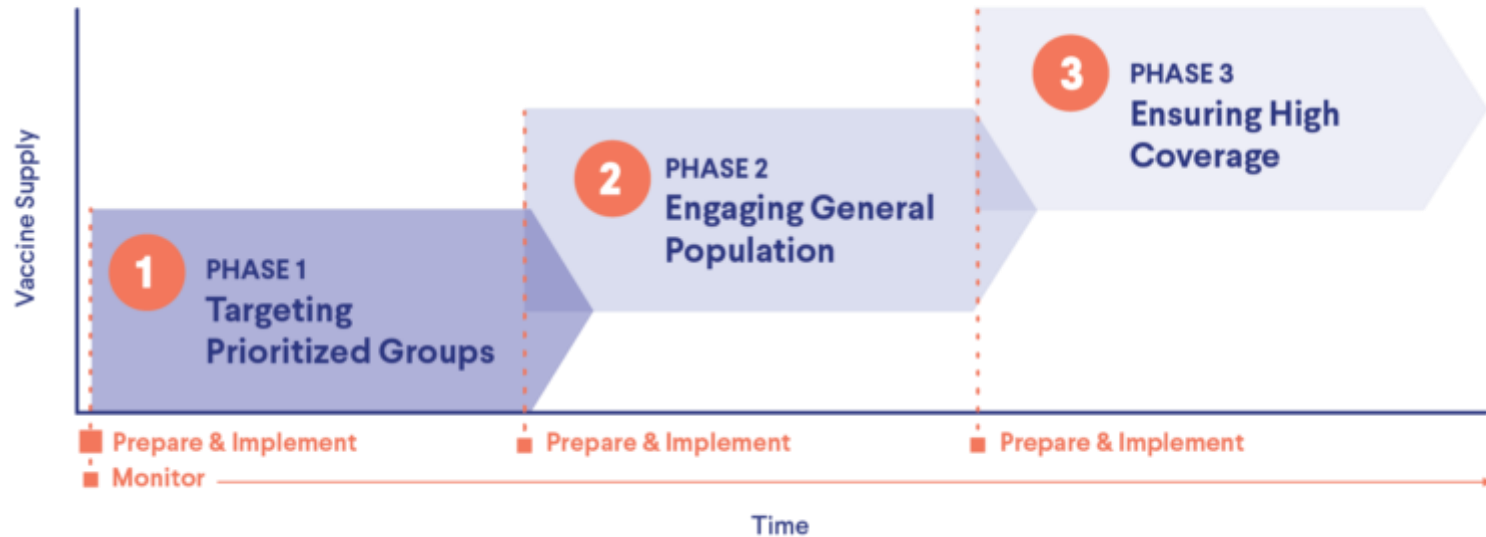
[www.samrc.ac.za/media-release/samrc-launches-study-evaluate-effectiveness-moderna-booster](http://www.samrc.ac.za/media-release/samrc-launches-study-evaluate-effectiveness-moderna-booster)

# STRATEGIES FOR COMMUNITY PARTNERSHIPS AND SCIENCE

- Use language that is locally acceptable and consider guidelines or develop one if needed.
  - LGBTQI community (and not, e.g., gay community) to reflect the diversity of the community unless a specific sub-group is meant to be referenced.
  - Consider using the terms “sexual orientation”, “gender identity”, and “gender expression”.
  - Use gender-neutral language (e.g., avoid “stewardess” and consider “flight attendant” instead).
  - Use terms that are inclusive of all gender identities (e.g. parents-to-be; expectant parents).
  - Raise awareness to current practices e.g. some children are raised by relatives and not their biological parents.
- Flexibility in our communications and surveys is key to participation.

# WHAT CAN WE DO BETTER?

## Vaccine Communication Strategy



# STRATEGIES FOR COMMUNITY PARTNERSHIPS AND SCIENCE

- Community science includes writing experiences with participants, members of community structures and policy makers.
- Open days for the research sites to community stakeholders and hold community science days.
- Assist with messages to be visual, simple, creative e.g. videos, plays, voice notes

## REASONS FOR APATHY

- Build trust in government, researchers, health sector.
- Build confidence by being part of social and community research programmes in your area.
- Resources for structural issues to me made available e.g. access NGOs like Gift of the Givers, Govt grants as hunger, malnutrition, unemployment and lack of housing are a priority for the nation.

## WHAT CAN WE DO BETTER?

- Add community engagement outcomes in submissions to local ethics committees.
- Capacity develop users of interventions including trial participants and develop mechanism to engage with users e.g. Participant Advocate or Advisory Groups.
- Partner with stakeholders who are skeptical hesitant and understand their perspectives.
- Less reactions and more action/responses to stakeholders and regulatory groups.



## SUMMARY

- Science is cycle of curiosity, questions, discovery and improvements.
- Collaboration, partnerships and team work is most effective with private and public sectors.
- Assess and critically follow the science to make informed choices, decisions and accept the consequences.

*“I have been impressed with the urgency of doing. Knowing is not enough; we must apply. Being willing is not enough; we must do”*

Leonardo da Vinci

*Together we can be significant*

# REFERENCES, RESOURCES

- <https://aids2022.org>
- <http://www.crvp.org> – Ethics, Human Rights and Development in Africa – talks
- <https://www.hanc.info> - [Understanding Science](#) videos update

# CONTACT DETAILS

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