

# CSSR Seminar

## Implementing Citizen Science and participatory research to empower communities in responsive science for social cohesion

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# OUTLINE

**Introduction:** Social Cohesion and its importance

**Citizen Science & Inclusive research**

**Two Examples of Citizen Science projects in SSA:** Processes and Outcomes

**Conclusion**

# Social Cohesion: Why is it important?

**Social cohesion** refers to the extent of connectedness and solidarity among groups in society.

## Two Dimensions:

1. Sense of belonging of a community



2. relationships among members within the community itself



Social Cohesion is a Driver of long-term prosperity and competitiveness

# Social Cohesion and inequality

Social cohesion exemplified. Rugby World Cup 2019.

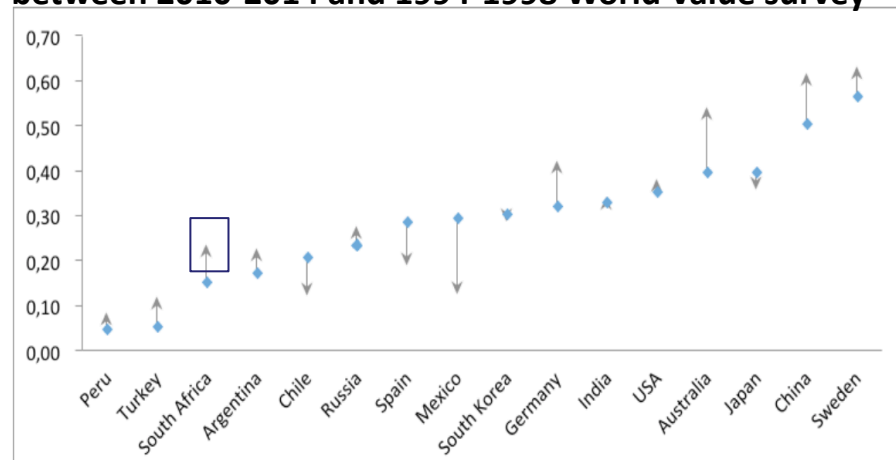


**Factors:**  
inequality, poverty, violence, gender conflicts, mistrust, etc

Level of trust – higher in more Equal rich countries



**Evolution of horizontal trust: Difference in trust in others between 2010-2014 and 1994-1998 World Value survey**



Source: Wilkinson & Pickett, The Spirit Level (2009)

Gianluca G, & Nicholas T. Social Cohesion, Global Governance & the Future of Politics: Understanding and fostering social cohesion, (2018)

# Participatory and Inclusive Research

## Participatory action research (PAR)

- an approach that emphasizes participation and action.
- Seeks to understand the specific environment and context, and support collaboration for a change.
- Emphasizes collective inquiry and experimentation grounded in experience and social history.

## Characteristics

- (1) participation by the people being studied;
- (2) inclusion of popular knowledge;
- (3) a focus on power and empowerment;
- (4) consciousness raising & education of the participants;
- 5) political action -decision making

But most of research programmes have been driven from **outside** the communities, and the continent.



## Locals must lead the way to African scientific capacity and solutions

September 15, 2020 4:36pm SAST



**THE CONVERSATION**

Academic rigour, journalistic flair

# What is Citizen Science?

Citizen Science is a broad concept:

Two distinguishable types:

1. **Contributory citizen science**, and
2. **Democratised citizen science**.

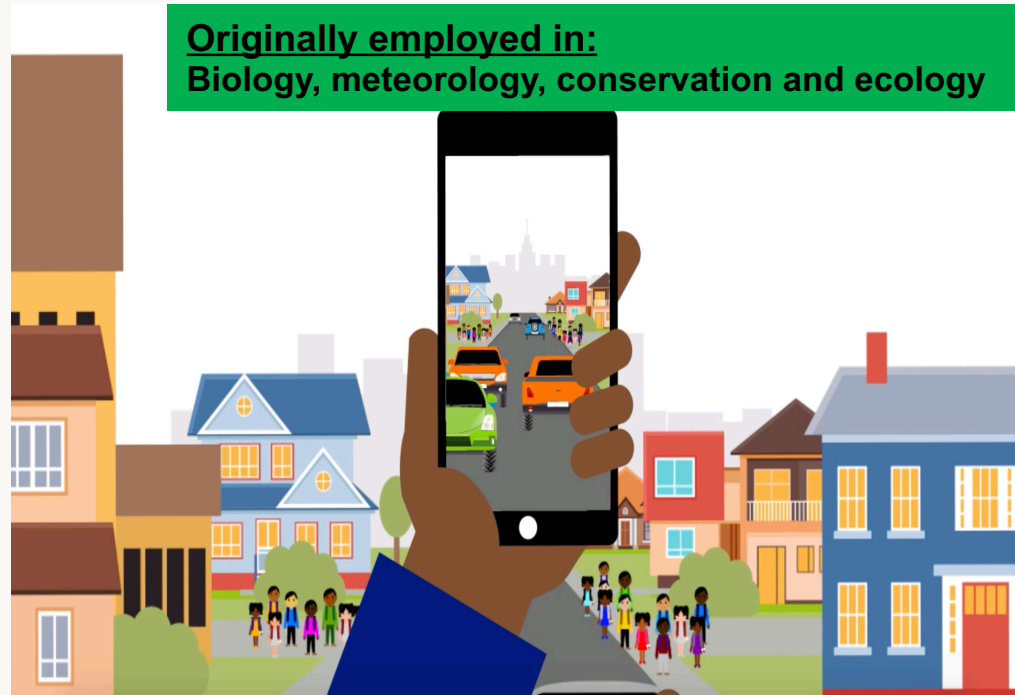
It lays emphasis on:

- robust community engagement
- participatory learning
- co-creation of knowledge
- advocacy for social action

It is closely aligned with participatory action research (PAR), which has been widely used in the field of public health

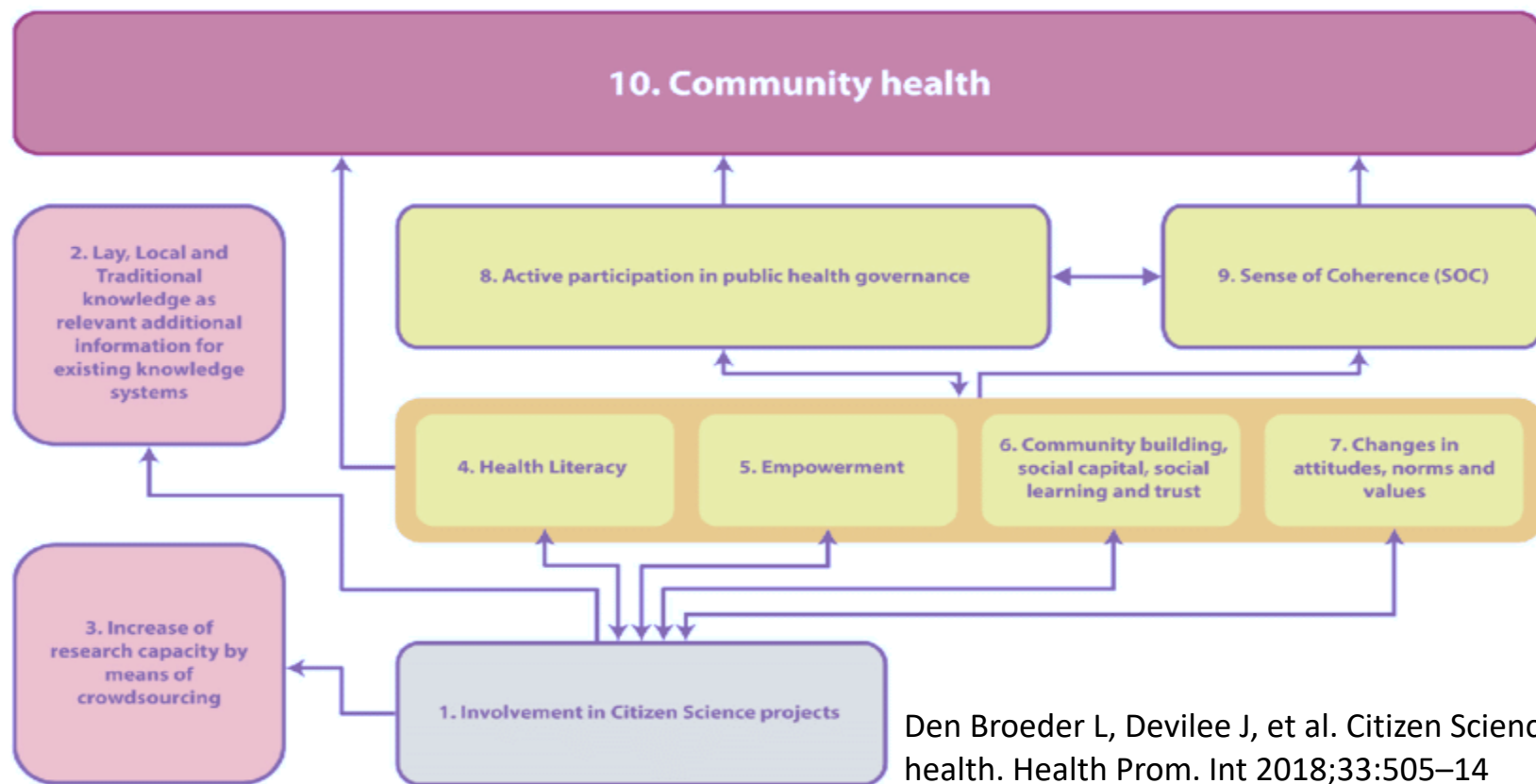
It is a **'By the People'** systematic research approach to building healthy communities

**Originally employed in:**  
Biology, meteorology, conservation and ecology



Dickinson JL, Shirk J, Bonter D, *et al.* *Front Ecol Environ* 2012;**10**:291–7.

# Effects of Citizen Science & PAR on health, governance and knowledge system



Den Broeder L, Devilee J, et al. Citizen Science for public health. *Health Prom. Int* 2018;33:505–14



# The Argument

- Science should be responsive to citizens' concerns and needs in their specific settings;
- that the process of producing reliable knowledge can be developed and enacted by citizens themselves with support from researchers; and
- that the local, contextual and real-world knowledge of citizens can be invaluable for gaining a more 'complete' understanding of a phenomenon and in finding real solutions to complex problems.

# Examples of Participatory Citizen Science projects in SSA

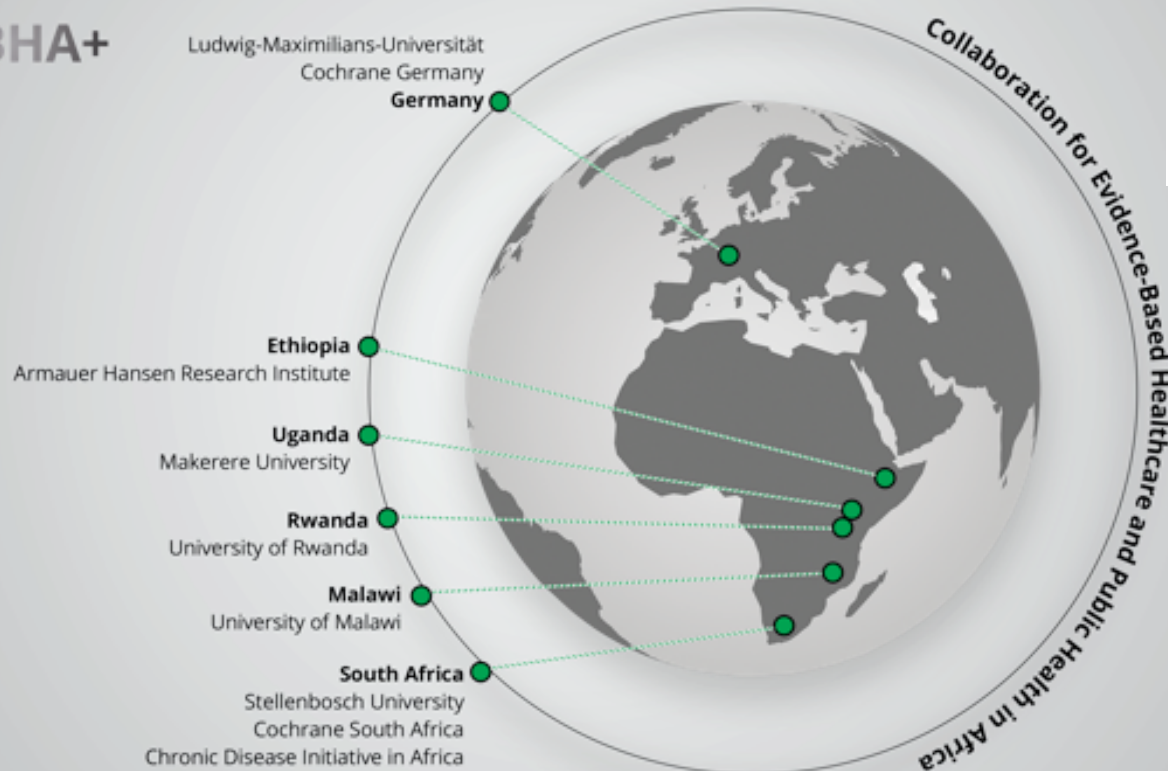
## Processes and Outcomes

# CEBHA+ Project Partners/Sites

(Collaboration for Evidence-Based Healthcare and Public Health in Africa)



Federal Ministry  
of Education  
and Research



# EXAMPLE 1: CEBHA+ Research Task 1

## GOAL:

Provide evidence-informed policies and practices on screening approaches for hypertension and diabetes and those at risk of cardiovascular disease in sub-Saharan African communities

## Key Tasks:

- To compare the effectiveness of lab-based and non-lab-based CVD risk scores algorithms in SSA countries (**Phase 1**)
- Conduct systematic reviews on different screening approaches (**RT2**)
- Conduct Citizen science participatory research on CVD risk screening and referrals using CHWs within PHC systems (**Phases 3**)

# Citizen Science Project Focus: Research Task 1

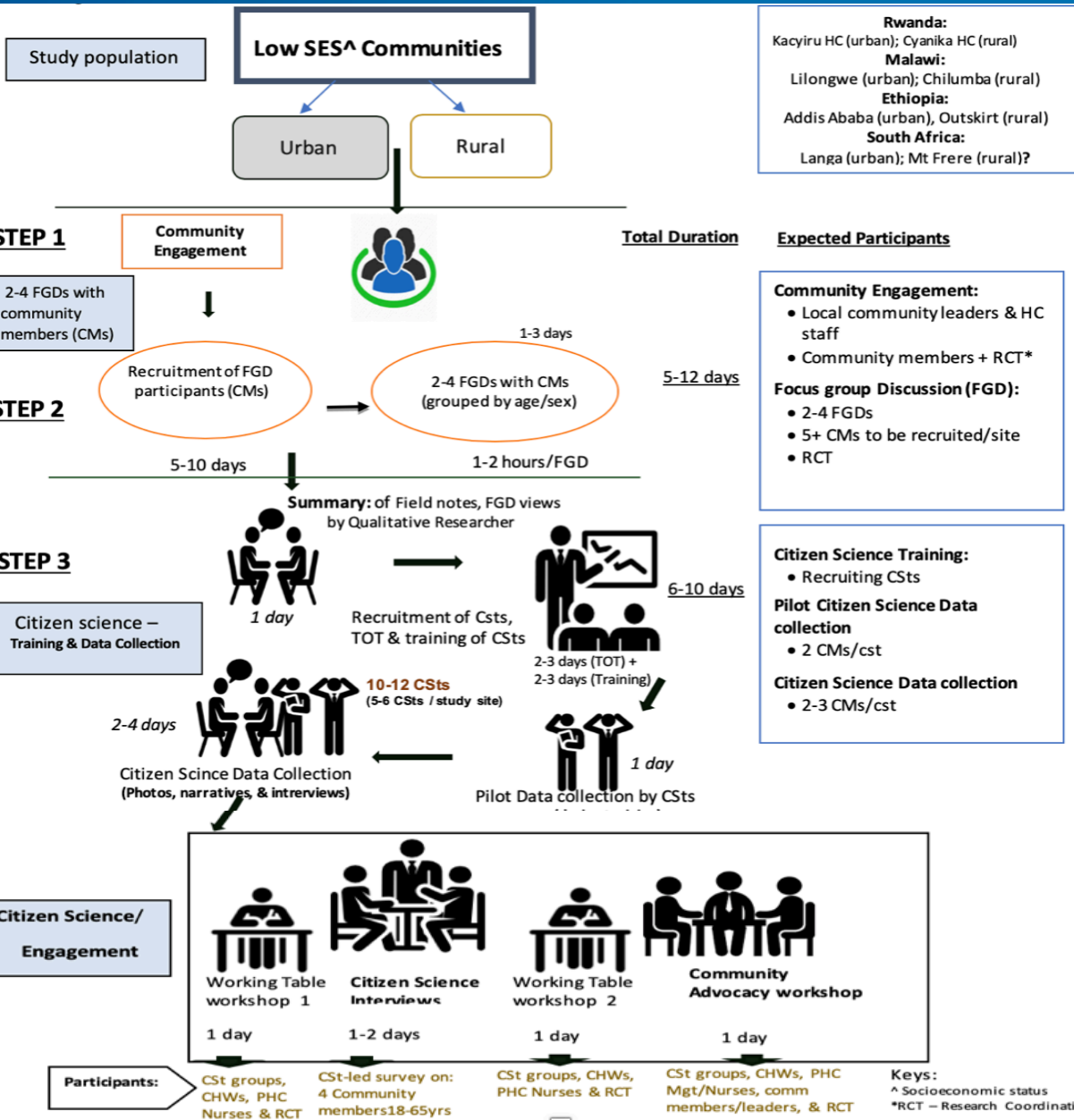
## Goal:

**Engaging communities to explore cardiovascular disease risk perception and developing communication strategies for CVD prevention in sub-Saharan African communities (Malawi, Rwanda, Ethiopia and South Africa)**

## Objectives:

- To explore how individuals in African communities perceive, interpret and communicate health risk.
- Training citizen scientists to gather, analyse and interpret data on CVD risk perception and communication in the community.
- Conduct citizen-scientist-led community advocacy with relevant stakeholders to facilitate identification and prioritizing of pilot intervention solutions to prevent CVD disease

# DESIGN/METHODS [FLOWCHART]



# Citizen Science Processes

## Discover



Discover aspects of the community that impact healthy living

## Discuss



Discuss findings with other citizen scientists

## Advocate

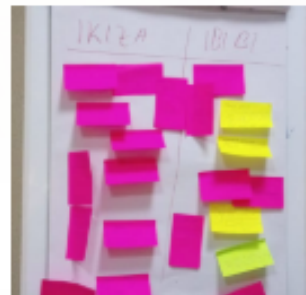
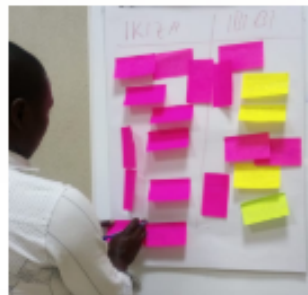
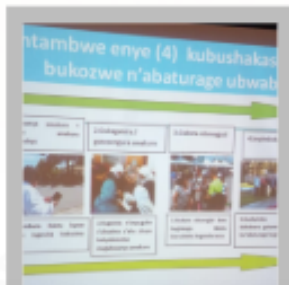


Advocate for local improvements

## Change



Create healthier communities



### We acknowledge.

Abby King and her team - Global Citizen Science Network for Health Equity ("Our Voice") led by the Stanford Prevention Centre, Stanford University, USA. <http://med.stanford.edu/ourvoice/the-global-network-right.html>

# Citizen Science + PAR – for CEBHA+

Lead Citizen Scientist in Adama Urban presents finding from CEBHA+ CVD Risk perception, communication Study.



**Present data  
(Advocacy workshop)**

**Community  
Engagement**

**Recruitment  
(Project teams, CSts)**

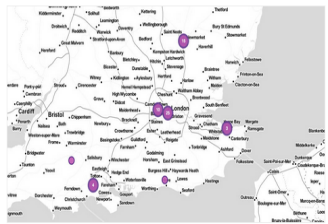
**Design tools &  
training (TOT)**



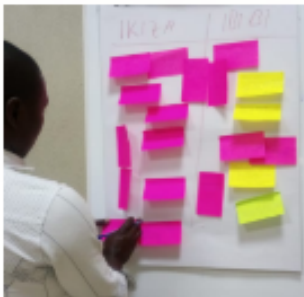
**Train CSts  
&  
Pilot Test**

**Learning Science  
Together**

**Data Analysis &  
Interrogation**



**Transcribe &  
arrange  
data/photo**



**CSt identify  
persons for  
Interviews**

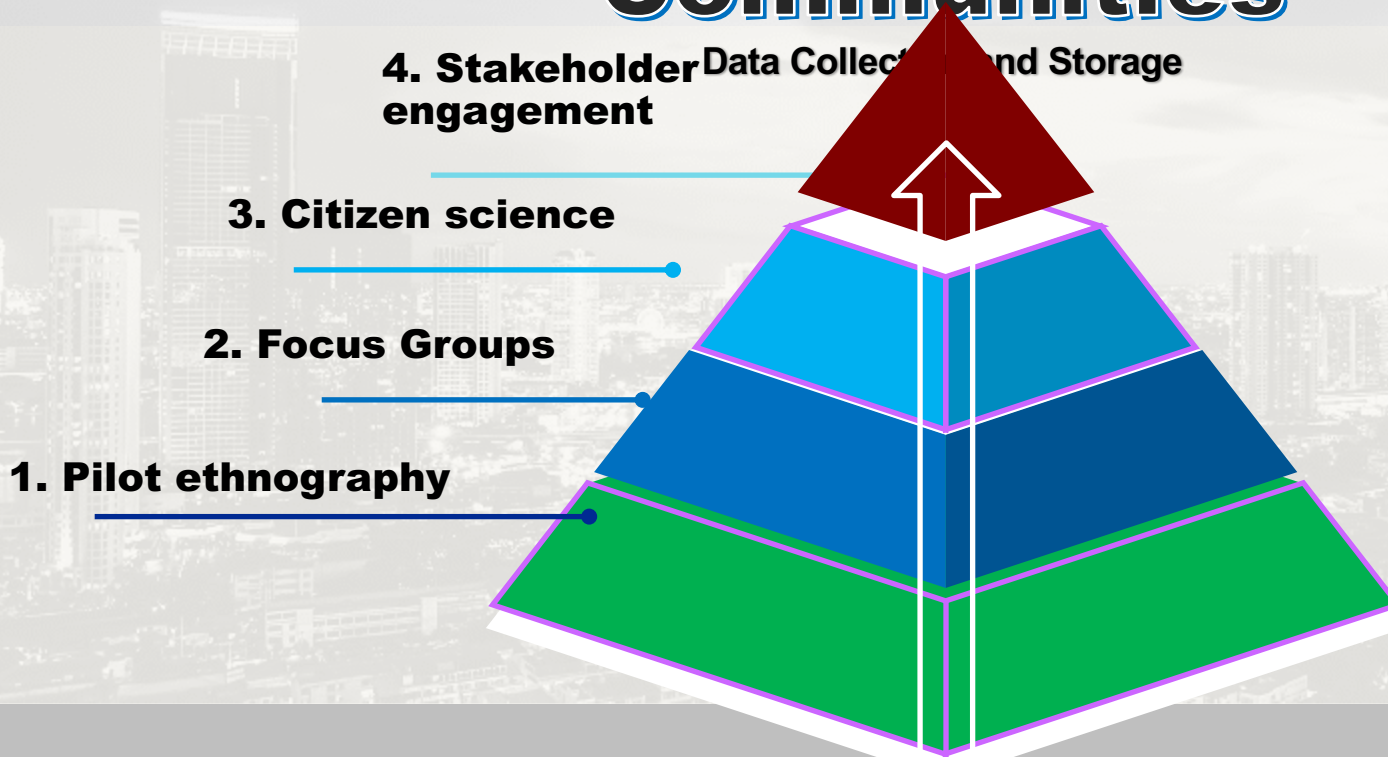


**Collect Data  
(mobile app)**



# Local Project team adapt Mobile app

## Engagement with Communities



1. **Create** your project and forms (Create, add questions, publish and share)
2. **Collect** data online or offline (download app, add project, and collect your data)
3. **View** and analyse
4. **Export** your data

# 1-DAY ADVOCACY WORKSHOP/MEETING



*Following data extraction and presentation of findings:*

**Stakeholders, CSTs & project team discussed implications of findings, and set strategies to communicate health risk**

# Preliminary Findings

## Qualitative findings: Pilot Ethnographic survey & FGDs

# Ethiopia

Themes	Rural	Urban
<b>General:</b> Disease, health, Heart, CVD	*Malaria, Typhoid, skin disease, etc.  *Awareness/ knowledge regarding CVD is very low	*Malaria, hypertension, diabetes. *High awareness/ knowledge regarding CVD *limited knowledge regarding CVD - among...
<b>Perceived threat:</b> Vulnerability/Threat	*Heavy work (farm work/long hours in the sun, hauling loads) *Majority – <b>Not vulnerable</b>	*... are exposed to... factors ... unbalanced diet ( fatty foods), ... Khat, and high intake of coffee ... as possible risk
<b>Concept of Risk:</b> (Disease and possible harm)	*Concept of ... difficult to ... *... the risk ... disease	*Concept was difficult *learned ones had associated risk with CVD
<div style="border: 1px solid red; padding: 5px;"> <ul style="list-style-type: none"> <li>• Conceptualizing health risk was unclear.</li> <li>• CVD risk perception was poor: CVD was associated with witchcraft, hard work and poverty, especially in rural communities.</li> </ul> </div>		
<b>Health Seeking Behaviour</b> (Behavioural Responses)	... harmful – if it <b>affects daily routine</b> activity; make one <b>bed ridden</b> ; <b>clinical impact</b> (urban); <b>long time to recover; incurable</b> ; potential to result in <b>death</b>	
<b>Communication:</b> (Interpretation/Presentation)	Attached colours to specific diseases Yellow – jaundice (liver disease) White – paleness (anaemia) Red – vitality (blood)	Red colour – <b>life threatening</b> , very harmful event Green/white - indicates less harmful

# Malawi

Themes	Rural	Urban
<b>General:</b> Disease, health, Heart, CVD	*Blood pressure (hypertension), and stroke considered harmful. good knowledge of NCDs generally - cancer, epilepsy/Asst	*Heart disease, CVD
<b>Perceived threat:</b> Vulnerability/Threat	Low understanding of risk Dietary intake/behaviour Poverty considered harmful to health CVD -	Health risk/risk Smoking, alcohol are looked as harmful to the heart *Poverty – intake of cheap food
<b>Concept of Disease</b> (Disease as harm)	was difficulty body	Risk presentation/communication - difficult Heart is likened to a motor vehicle? - a person's body Knowledge on risk, prevention and treatment limited
	High risk/harm is associated with <b>death and severe signs and symptoms</b>	<b>term or frequent illnesses</b> , HIV/AIDS,
<b>Health Seeking:</b> (Behaviour intentions)	Heart disease is associated with witchcraft. Health seeking - Traditional and religious	
<b>Communication:</b> (Interpretation/Presentation)	Green = low risk or least harm ; Red = High risk Health workers were the preferred source of communication relating to heart disease.	Through community meetings gatherings/funerals. Community/household outreach/

**Colours** were associated with specific diseases and severity levels; **Red** colour - attributed to life threatening events; could mean vitality and good health (in one rural community). **Green, amber, white** were attributed to specific diseases, whereas **black** colour often link with **death**.

**Participants were willing to attend a clinic if referred by CHW**

# Ethiopia

Themes	Rural	Urban
<p><b>General:</b> Disease, health, Heart, CVD</p>	<p>*Malaria, Typhoid, skin disease, etc.</p> <p>*Awareness/ knowledge regarding CVD is very low</p>	<p>*Malaria, hypertension, diabetes.</p> <p>*High awareness/ knowledge regarding CVD</p> <p>*limited knowledge of CVD - among women</p>
<p><b>Perceived threat:</b> Vulnerability/Threat</p>	<p>*Heavy work (farm work/long hours in the sun, hauling loads)</p> <p>*Majority – <b>Not vulnerable</b> to CVD</p>	<p>*Some perceived they are exposed to possible risk factors</p> <p>Alcohol, smoking, unbalanced diet (fatty foods), stress, chewing <b>Khat</b>, and high intake of coffee mentioned as possible risk</p>
<p><b>Concept of Risk:</b> (Disease and possible harm)</p>	<p>*Concept of risk (possibility) was difficulty</p> <p>*Majority do not associate risk factors with heart disease</p>	<p>*Concept was difficulty</p> <p>*learned ones had associated risk with CVD</p>
<p><b>Disease are harmful</b> – if it <b>affects daily routine</b> activity; make one <b>bed ridden</b>; <b>economical impact</b> (urban); <b>long time to recover</b>; <b>incurable</b>; potential to result in <b>death</b></p>		
<p><b>Health Seeking:</b> (Behaviour intensions)</p>	<p>Visit traditional healers and religious places for heart related diseases/issues (including psycho-social challenges)</p>	
<p><b>Communication:</b> (Interpretation/Presentation)</p>	<p>Attached colours to specific diseases</p> <p>Yellow – jaundice (liver disease)</p> <p>White – paleness (anaemia)</p> <p>Red – vitality (blood)</p>	<p>Red colour – <b>life threatening</b>, very harmful event</p> <p>Green/white - indicates less harmful</p>

# Malawi

Themes	Rural	Urban
<b>General:</b> Disease, health, Heart, CVD	*Blood pressure (hypertension), and stroke considered harmful. good knowledge of NCDs generally - cancer, epilepsy/Asthma	*misunderstandings around heart disease , *hypertension considered as CVD
<b>Perceived threat:</b> Vulnerability/Threat	Low understanding of risk factors - Dietary intake/behaviour, smoking Poverty considered major risk factor of CVD –associated with - anxiety, stress excessive beer drinking, breakdown of relationships (young women)	Good understanding of health risk/risk factors *Diet, smoking, alcohol are looked as harmful to the heart *Poverty – intake of cheap food
<b>Concept of Risk:</b> (Disease and possible harm)	*Concept of risk (possibility) was difficulty Heart is the engine of the body’	Risk presentation/quantification - difficult Heart is likened to a ‘motor vehicle’s engine’ in a person’s body Knowledge on risk, prevention and treatment limited
	High risk/harm is associated with <b>long term or frequent illnesses</b> , HIV/AIDS, <b>death and severe signs and symptoms</b>	
<b>Health Seeking:</b> (Behaviour intensions)	Heart disease is associated with witchcraft. Health seeking - Traditional and religious houses	
<b>Communication:</b> (Interpretation/Presentation)	Green = low risk or least harm ; Red = High risk  Health workers were the preferred source of communication relating to heart disease.	Through community meetings gatherings/funerals. Community/household outreach/

# OUTCOMES: Engagement & Advocacy

- Create CVD risk awareness in communities
- Trained 6-10 project staff and 12-15 community members in each country on Citizen science and mobile data collection, advocacy
- Over 30 stakeholders in relevant sectors engaged with and participated in advocacy workshop in each study site
- **CS findings provided priority areas needing intervention**
- Community Stakeholders' advocacy led to planned pilot interventions on NCD risk prevention campaigns in Ethiopia.
- Impact at local, regional and national levels

## Overall:

- **Stakeholders' /community engagement and advocacy afforded opportunity to chat possible ways to improve social cohesion**

# EXAMPLE 2



## Global Public Health

An International Journal for Research, Policy and Practice

ISSN: 1744-1692 (Print) 1744-1706 (Online) Journal homepage: <https://www.tandfonline.com/loi/rgph20>

## A citizen science approach to determine perceived barriers and promoters of physical activity in a low-income South African community

Feyisayo A. Odunitan-Wayas, Nicola Hamann, Nandipha A. Sinyanya, Abby C. King, Ann Banchoff, Sandra J. Winter, Sharief Hendricks, Kufre J. Okop & Estelle V. Lambert

# Perceive barriers

The study's objective was to assess the feasibility of using citizen science to identify and address physical activity (PA) barriers in a low-income South African community.

We purposively selected as citizen scientists, eleven participants (21–45 years) from a cohort study who expressed interest in becoming physically active or were already active.

They used the Stanford Neighborhood Discovery Tool mobile application

Thereafter, in a facilitated workshop

## **Results:**

Themes identified as priorities that hindered citizen scientists' PA were dirt, sidewalks appropriated by vendors or homeowners, parks and gym vandalism, and personal safety fears. Access to stadiums and parks enabled PA.

# Summary & Conclusion

- **Citizen science and planned engagement of citizens in research can support participatory engagement for inclusive learning, co-designing, and co-creation intervention actions to address CVD prevention.**
- science should be responsive to citizens' concerns and needs;
- that the process of producing reliable knowledge can be developed and enacted by citizens themselves with support from researchers;
- and that the local, contextual and real-world knowledge of citizens can be invaluable for gaining a more 'complete' understanding of a phenomenon and in finding real solutions to complex problems
  
- **Learning in a supportive environment and engagement of community members as Citizen Scientists can engender social cohesion**



- **Evaluating the intervention actions needs continual efforts of**

# References

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# Acknowledgement

