Public engagement – towards a research-smart community

MRC/Wits Rural Public Health and Health Transitions Unit (Agincourt)
Rhian Twine, Simon Khoza, Audrey Khosa, Jeffrey Tibane, Kathy Kahn (and all of you!!)

The value of an HDSS is cumulative

More and more projects nested in MRC/Wits Agincourt Unit

Census year	1992	1993	1994	1995	1996	1997	1998	1999	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012	2013	2014	2015	2015
Modules																									
Education	■					■					■				■			■			■			■	
Labour									■				■				■				■				
Household assets										■		■		■		■		■		■		■	■	■	■
Temporary migrations											■					■					■				
Child Care Grants											■			■			■			■					
Health Care Utilisation												■			■				■					■	
Food Security													■			■			■			■			■
Adult Health															■				■		■				
Father support																■	■								
Vital Documents														■		■									

Current studies **in the field** (collaborative model)

Health and social responses

- PEECHi - Programme for the Economic Evaluation of Maternal and Child Health Interventions)
- Vunene - Evaluation of the Integrated Chronic Disease Management (ICDM) model in rural South Africa
- Engaging Traditional Healers

Livelihoods health and wellbeing

- Environmental monitoring

Child and adolescent health and development

- Conditional Cash Transfer
- One Man Can community mobilisation
- Access to care for HIV positive adolescent girls

Adult health, ageing and wellbeing

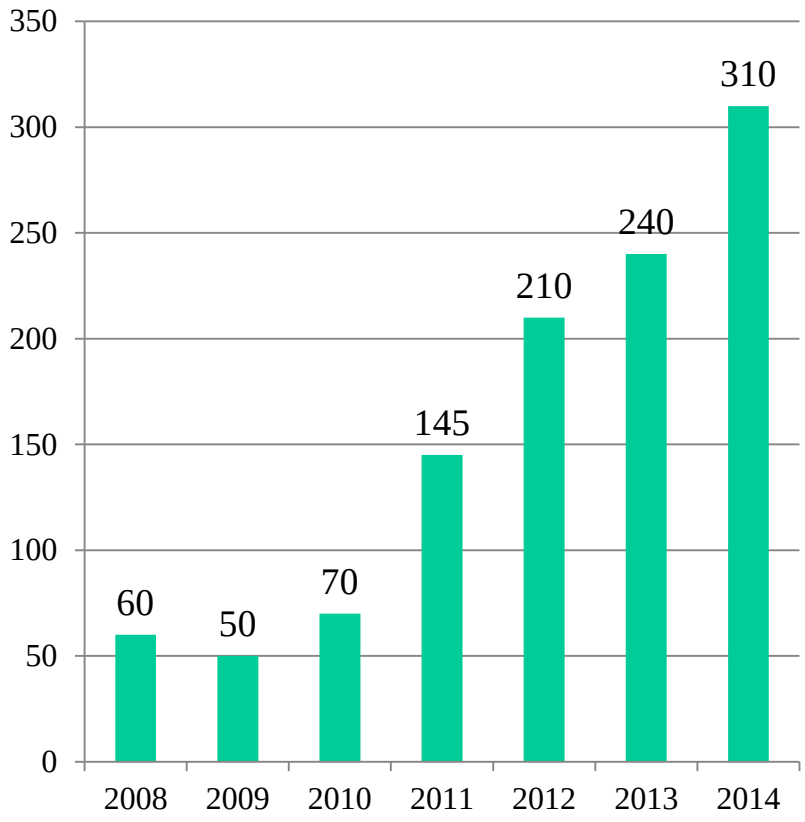
- AWIGEN - Genomic and Environmental Risk Factors for Cardiometabolic Disease in Africans
- HAALSI - Health and Aging in Africa: Longitudinal Studies of INDEPTH communities

Levels, trends and transitions

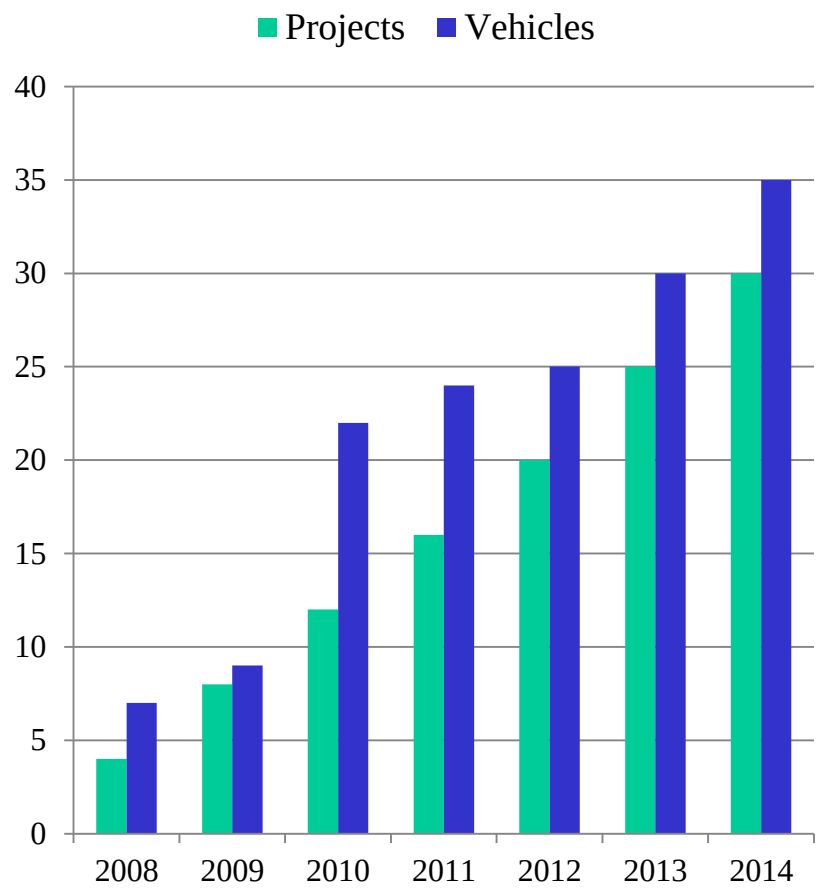
- Census
- Verbal autopsy/ mortality
- Migration reconciliation
- Community feedback

Staff and infrastructure changes from 2008

Staff numbers



Projects and vehicles



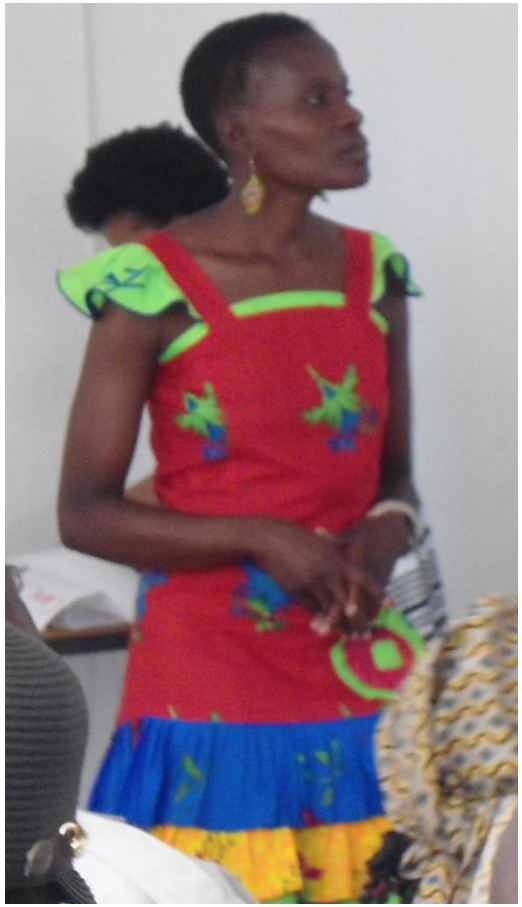
What does this make us consider?

If we believe in the value of longitudinal research, we need to ensure we can carry it out for a long time in same geographical area/population

- Rapport with community key to sustainability
  - Trust and respect (or are we just 'keeping an already accommodating community 'sweet'?)
  - Formerly marginalised and thus disadvantaged community
  - Community has its own culture, structures and history
  - Individuals in site have agency
- Very transitions we record
    - ↑ SES
    - ↑ understanding of rights vs responsibilities
    - ↑ understanding of importance of data by leaders
- Research fatigue (?an outside perception)
- Are the public engagement activities currently underway effective?

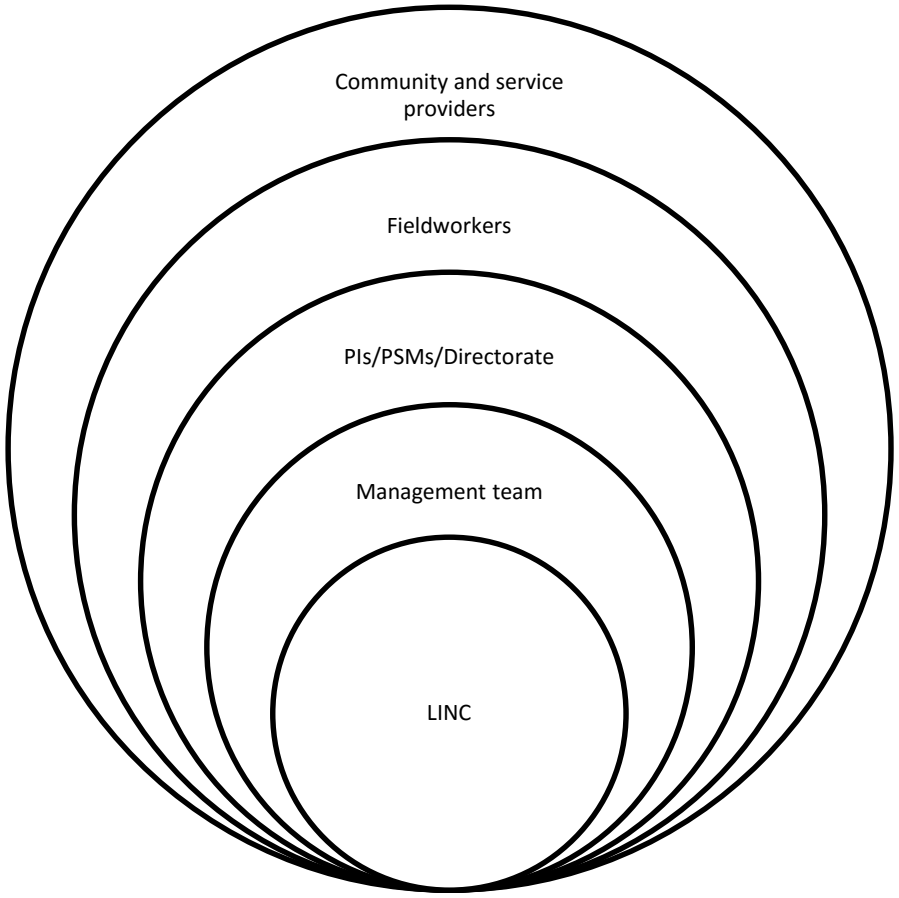
Who worries – whole unit – invests in

Learning, Information dissemination and Networking with Communities (LINC) Office



LINC Office Aim

The LINC office, working together with the community, service providers, researchers, fieldworkers and management, enables effective and appropriate public engagement in research



Circles of influence on public engagement

LINC Office Principles

- Engagement BEFORE (community entry) , DURING (procedural ethics) and AFTER (community feedback) projects
- Sustainable
- Trust and respect
- “Information is our currency”
- Work with not against local structures
- Focus on the longevity of the HDSS
- Engagement with
  - Province, District, Local DoE, DoH, DOSD,
  - Local and District Municipality,
  - HBC and other NGOs
  - Churches
- Guided by ethics and ethics committees

LINC Office Activities

- Community entry for all projects
- Ethics of practice – referrals/myths/rumours/reports on progress/feedback of individual clinically relevant results
- Knowledge dissemination
  - Household level
  - Village level
  - Ward level
  - Sub district level – DOH/DoE/DoSD/Municipality
  - District level
  - Provincial level
- Networking
- Tertiary admissions project

?Proof of Research Smart Community?

- Low refusal rates
- Low attrition
- High attendance rates at weekend ‘camps’
- Appreciation for point of care results

?Is there Research Fatigue?

No empirical evidence just

- Some mutterings from fieldworkers
  - Complaints re questionnaires too long
  - Sometimes refusals as ‘sick of Wits’ yet
  - Outside villages wanting in
- Few (very few) permanent exclusions of households (employment issues mainly)
- Take into account
  - Increase in field site population
  - Increase in number of projects therefore more participants to say no
  - Households involved in more than one project every two years

A few of our challenges

- Improving feedback loop to inform more research/service
  - Good at local community engagement but need to become more effective at engaging District and Province policy implementers
  - Is research taking into account current policy and practice?
  - Good at community entry but need more effective reporting to PIs/PSMs
- Growing community expectations of a visibly growing organisation
- Which projects to include in the HDSS site
  - Benefit to thickening HDSS vs benefit to project
  - Increase LINC team if we move to HYAK model

What led to our work with MCWY and Nutrition

Work with Programme on Economic Evaluation of Child and Maternal Health interventions project on Lives saved Tool (LisT)

i. 4th May 2014 – baseline data gathered for LisT tool
ii. 12th August 2014 – more LisT data and discuss child CoD
iii. 23rd May 2015 - more LisT data gathered and presentation of CoD of children dying at home fact sheet
iv. 24th July 2015 – discussion on CoD of children dying at home and first discussion on social causes of death with VAPAR team
v. 4th April 2016 feedback of LisT tool – comments incorporated into final report

What led to our work with MCWY and Nutrition

Work with VAPAR

i. 5th October - follow up on VAPAR health care utilisation work based on questions from meeting on 23 May

ii. Heads of CMH Mpumalanga and Bushbuckridge attended a VAPAR focus group in the Agincourt field site

iii. Members of CMH Directorate co-authored a paper on the verbal autopsy methodology in relation to social causes of death

iv. Members of CMH Directorate co-applicants in a funding proposal to the MRC-UK on furthering work on the social causes of death.

v. 22nd February 2016 – discussions on further VAPAR work

Current future plans

1. Formal MOU with MRC/Wits Agincourt so that the unit can be invited to higher level planning meetings
2. DoH request for Agincourt to work with the Mpumalanga Child and Maternal Health Directorate to organise a local Imbizo in early 2016 to address lack of knowledge in the community especially with regards to identifying serious childhood illness. This is now planned for 21st November 2016

Thank you