





## Linking the HDSS and the health care system through patient-held records for the treatment of epilepsy

**Ryan G. Wagner**  
Xavier Gomez-Olive  
Steve Tollman  
Charles Newton

INDEPTH International Scientific Conference (ISC)  
Maputo, Mozambique  
October 24, 2011



*From a simple research tool for record linkage to unintentional interventions...*

## Background: SEEDS

*Studies of the Epidemiology of Epilepsy in the Demographic Surveillance Sites*

- 5 INDEPTH sites across sub-Saharan Africa
- Aim to study the prevalence, risk factors and outcome of epilepsy






## SEEDS' Studies

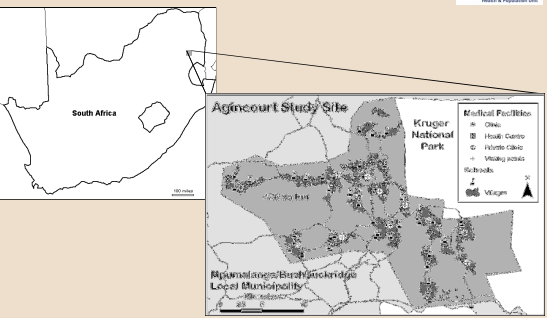


Ongoing demographic surveillance of uniquely identified individuals in a demarcated areas (DSS)

```

    graph TD
      A[Survey done in 5 INDEPTH DSS sites to identify cases of ACE] --> B[Study A Prevalence of ACE]
      A --> C[Controls matched to cases]
      C --> D[Study B Identification of risk factors for ACE]
      C --> E[Follow-up cases for 3-4 years and identify cases accessing and using treatment]
      E --> F[Study C Magnitude and risk factors of treatment gap]
      E --> G[Study D Calculate risk ratio for Death]
      E --> H[Record Deaths]
      H --> I[Study E Identify risk factors for death]
  
```





## SEEDS-Agincourt

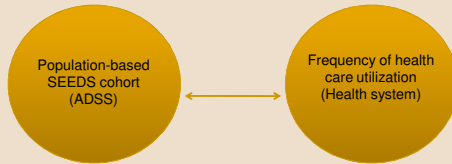
## SEEDS-Cohort Study

- "Patients with ACE will be followed up in the local clinic...for a period of 3- 4 years..."
- Agincourt DSS has 6 public health clinics, 1 larger public health centre and 1 private health centre specializing in TB/HIV care
  - It would prove difficult to follow-up patients diagnosed as having epilepsy in the DSS solely in the clinics as not all patients attend the clinic
  - Furthermore, all patients do not attend single clinic, rather multiple clinics are utilized



## Statement of Problem

How do you effectively link the DSS with the health system to examine health care utilization (clinic visits)?

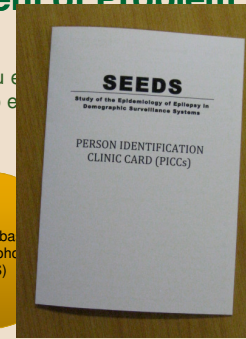


INDEPTH Network

## Statement of Problem

How do you effectively link the DSS with the health system to examine health care utilization (clinic visits)?

Population-based SEEDS cohort (ADSS) ↔ Frequency of health care utilization (Health system)



INDEPTH Network

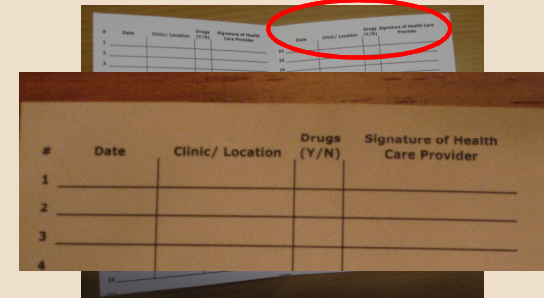
## PICCs: The Research Tool

### Personal Identification Clinic Card

- Serves as a patient-held link between the demographic surveillance site and the health care system
- Card completed by health care provider during visit
  - Information collected includes date and location of visit to health facilities, whether drugs were prescribed and asks for a signature of the health care provider



INDEPTH Network



INDEPTH Network

## The Linkage Methodology

- Information collected during the health care visit is then collected during routine household visits by the fieldworker
- This information is entered into the database and a list of clinic visits is generated
- Fieldworkers then visit each clinic and compare the information collected on the PICCs card to the clinic registry



INDEPTH Network

## Results from one clinic

- Took place in one clinic over 12-month period
- 100 PICCs entries, from 19 people with epilepsy who regularly attend the clinic were compared with clinic records
  - 51 records (51%) were matched in both records
  - 7 entries (7%) differed by dates within the same month
  - 42 records (42%) were not found in the clinic registry, though PICCs entry had health care workers' signature



INDEPTH Network

## Findings of the PICCs



- Apparent lack of complete data within primary health care clinic registers
- Patient-held records may more accurately reflect health care visits than clinic patient logs.
- Furthermore, patient-held records have shown to be a successful, and accurate link between the HDSS and the health care system



INDEPTH Network

## Unintentional Interventions in Clinics



- Nurses now use PICCs cards as way to identify people with epilepsy and 'fast-track' them for chronic epilepsy medication
- Nurses suggest that PICCs cards have increased adherence (analysis still pending)
- Nurses using PICCs cards as a way to confirm clinic visits



INDEPTH Network

## Limitations of PICCS



- High frequency of misplaced cards (roughly 30% of individuals required a second card)
  - Possible consequences for misplaced card
- Refusal by health care workers to complete cards ("not our work")
  - Requirement of health care workers' 'buy-in'



INDEPTH Network

## Future Directions of Research



- Currently comparing and analyzing results from other 5 clinics in Agincourt DSS to allow for more robust findings
- Comparison of patient files, clinic log books and PICCs cards
- Expansion of PICCs card to include other chronic diseases
- Possible use of PICCs at other SEEDS sites



INDEPTH Network

## From research tool...



- Successfully allowed for the linkage of SEEDS population-based cohort and health care system
- Indicated health care system's current record keeping may not be complete
- ...to unintentional intervention.
  - Has led to nurses 'fast-tracking' people with epilepsy due to quick identification with PICCs
  - Has possibility increase adherence through social pressure (fieldworker visits)



INDEPTH Network

## Acknowledgements



- The multi-site SEEDS study was funded by the Wellcome Trust
- INDEPTH support through providing a travel award for participation in this conference

### Agincourt fieldworkers

- Nkhensani Thoko Machave
- Charity Mnisi

Thank You!



INDEPTH Network