Studies of Epilepsy Epidemiology in Demographic Sites (SEEDS)

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Specific Aims

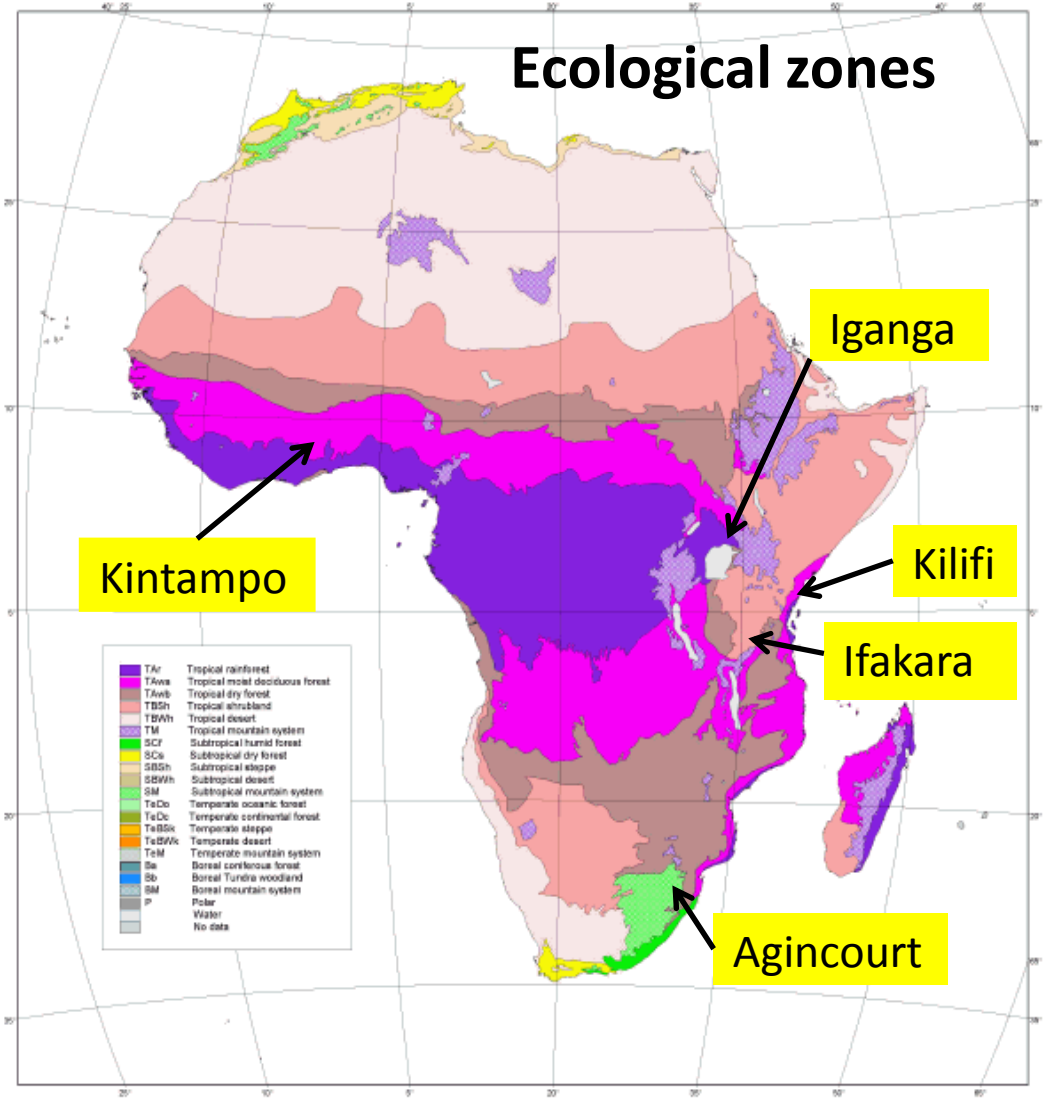
- prevalence of active convulsive epilepsy (ACE) in resource poor countries
  - easiest to identify
  - associated with most stigma
  - associated with most mortality
  - can be controlled with inexpensive anti-epileptic drugs
- attributable fraction of preventable risk factors for ACE
  - particularly preventable causes e.g. parasitic diseases
- magnitude and risk factors for mortality in epilepsy
- magnitude and risk factors of the treatment gap

SEEDS

- In Demographic Surveillance System (DSS) sites within the INDEPTH Network
- Strength of the DSS framework
  - Regular census → accurate denominator
  - Geographically defined populations
  - Infrastructure for efficient and prolonged follow-up
- Nested within on-going census in the DSS

Study Sites

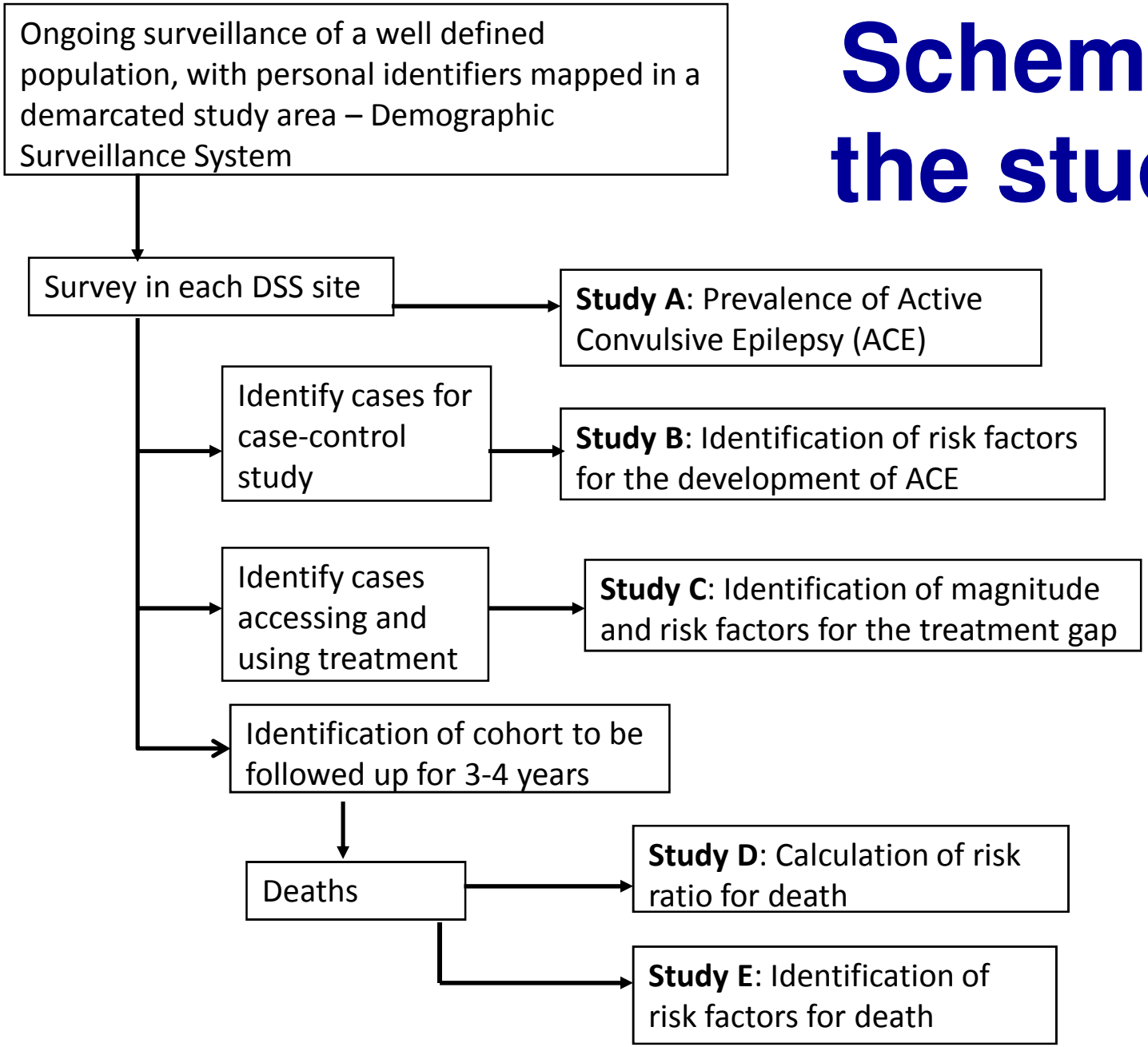
- 12 INDEPTH sites expressed interest
- 5 DSS sites chosen for
  - endemicity of parasitic risk factors
    - Neurocysticersosis
    - Toxocara sp
    - Toxoplasmosis
    - Onchocerciasis
    - Malaria
- cost and logistical



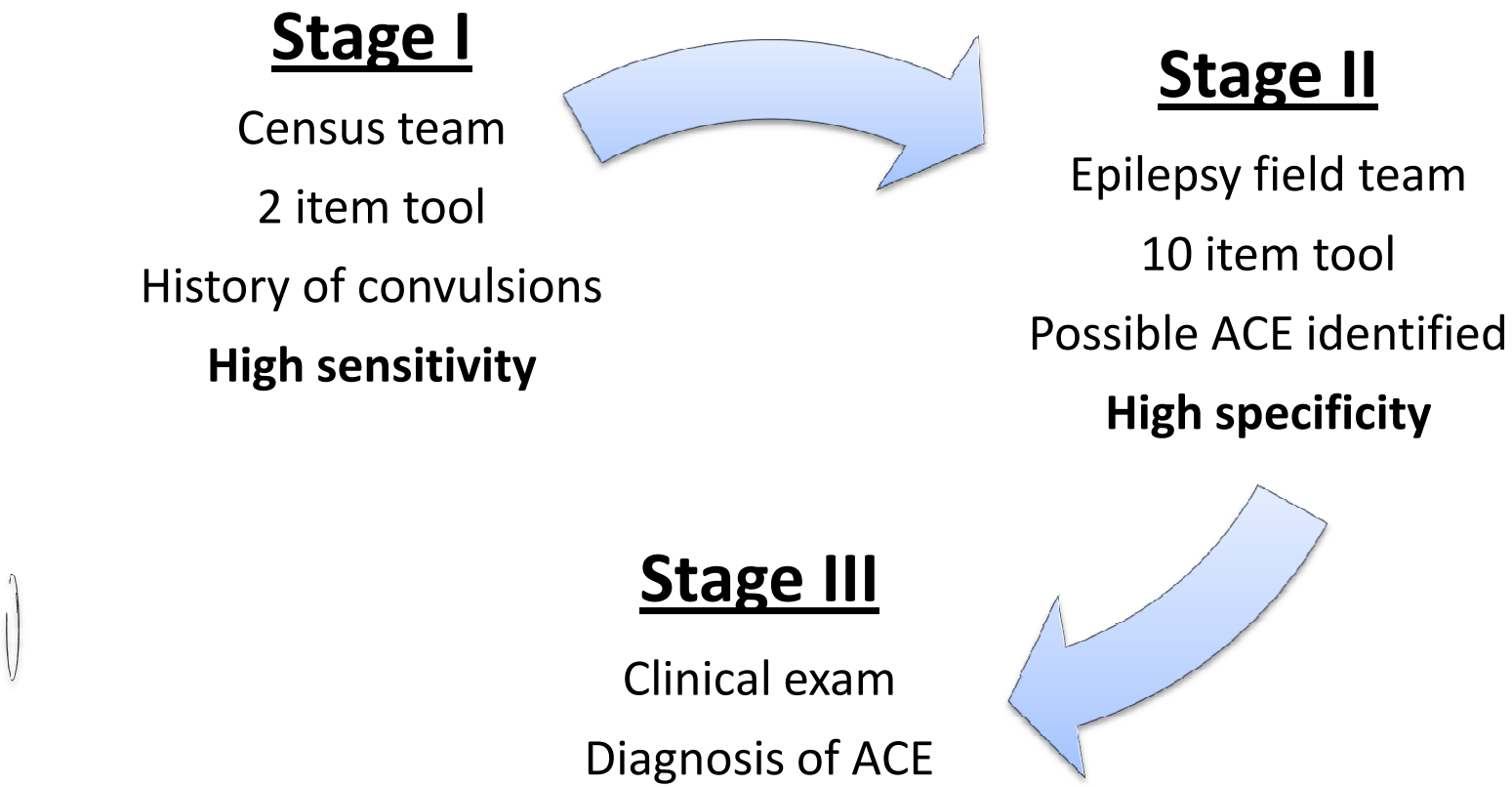
SEEDS study sites

HDSS Site	Country	Population	Census per yr
Agincourt	South Africa	84,000	1
Ifakara	Tanzania	93,000	3
Iganga/Mayuge	Uganda	68,000	3
Kilifi	Kenya	260,000	2
Kintampo	Ghana	130,000	2
Total		**685,000**	

Schema of the studies



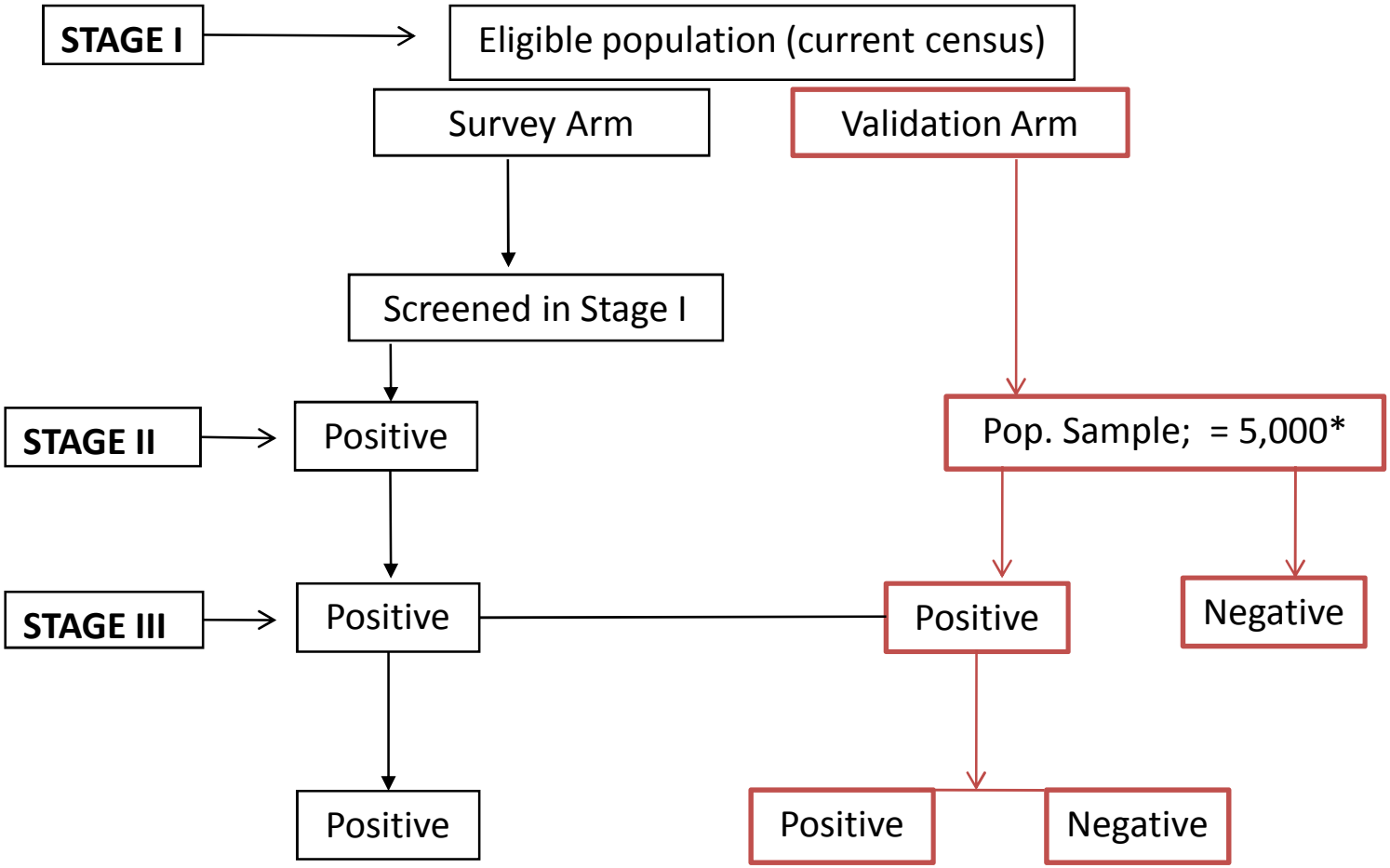
Surveys to estimate prevalence of ACE



Survey tools

- Questionnaires based on those used in international studies
- Terminology – derived from FGD
  - Pre-tested outside the study areas
  - Refined by field workers during training
- Forward translation into vernacular and independent back translation into English
- Reliability: questions repeated in Stages I & II

3-stage method



Summary of ACE prevalence

Site	Population	Cases of ACE	Cases fulfilled definition of residency	Crude prevalence (95% CI)	Adjusted prevalence (95% CI)	Controls
Kilifi	233,881	762	699	3.0 (2.8-3.2)	3.8 (3.5-4.0)	525
Agincourt	82,917	232	191	2.3 (2.0-2.6)	2.7 (2.3-3.0)	286
Iganga	68,808	278	134	2.4 (2.0-2.8)	5.5 (4.5-6.4)	247
Ifakara	99,375	442	353	3.6 (3.2-3.9)	6.5 (5.9-7.0)	567
Kintampo	135,172	-	-	-	-	-
TOTAL	**620,151**	**1,714**	**1,377**			**1,625**

Problems encountered

Sites differed with regards:

- terminology for convulsions/seizures
  - Depends upon the perceived cause of epilepsy
- methods of census
- data handling
  - single entry
  - data brought on a weekly rather than daily
  - delay in entering the census data
- population mobile
  - Any delays between the stages resulted in lost to follow-up

Future SEEDS studies

- Verbal Autopsy data on epilepsy
  - Mathew Alexander, Ifakara, Tanzania
- Cost effectiveness study
  - Ryan Wagner, Agincourt, South Africa
- Psychiatric co-morbidity
  - Kintampo
- Funding for survey in other sites
  - Pune, Hanif Shaikh
- Genetic studies
  - Definition of the phenotype

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  - Xavier Gomes
  - Kathy Kahn
  - Steve Tollman
- Iganga/Muyage, Uganda
  - Angelina Kakooza
  - Donald Ndyomughenyi
  - Stephan Petersen
  - Georges Pariyo
- Ifakara, Tanzania
  - Mathew Alexander
  - Honorati Masanja
- Kintampo, Ghana
  - Bright Akpalu
  - Ken Ae-Ngebise
  - Albert Akpalu
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  - Steve White
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  - Martin Prince
  - Victor Doku
- London School of Hygiene and Tropical Medicine, UK
  - Christian Bottomley
  - Immo Kleinschmidt
  - Andy Hall

Future Neurological studies

- Stroke
  - Myles Connor: mconnor@staffmail.ed.ac.uk
- Parkinson's disease
  - Richard Walker: richard.walker@nhct.nhs.uk