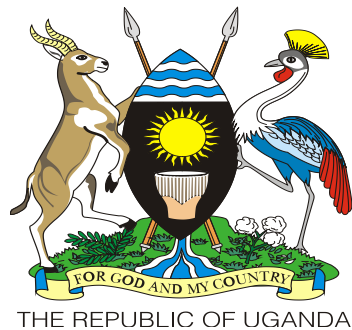


Uganda Sickle Survey Results and Neonatal Screening Program

Charles Kiyaga
National Sickle Cell Coordinator
CPHL, Ministry of Health



Study Questions

1. What is the prevalence of sickle cell trait and disease in Uganda, by region and district?
2. What is the distribution of sickle cell trait across the country?
3. What is the relationship between sickle cell trait and malaria prevalence?
4. What is the early mortality of sickle cell disease?
5. What is the co-morbidity of HIV and sickle cell disease?

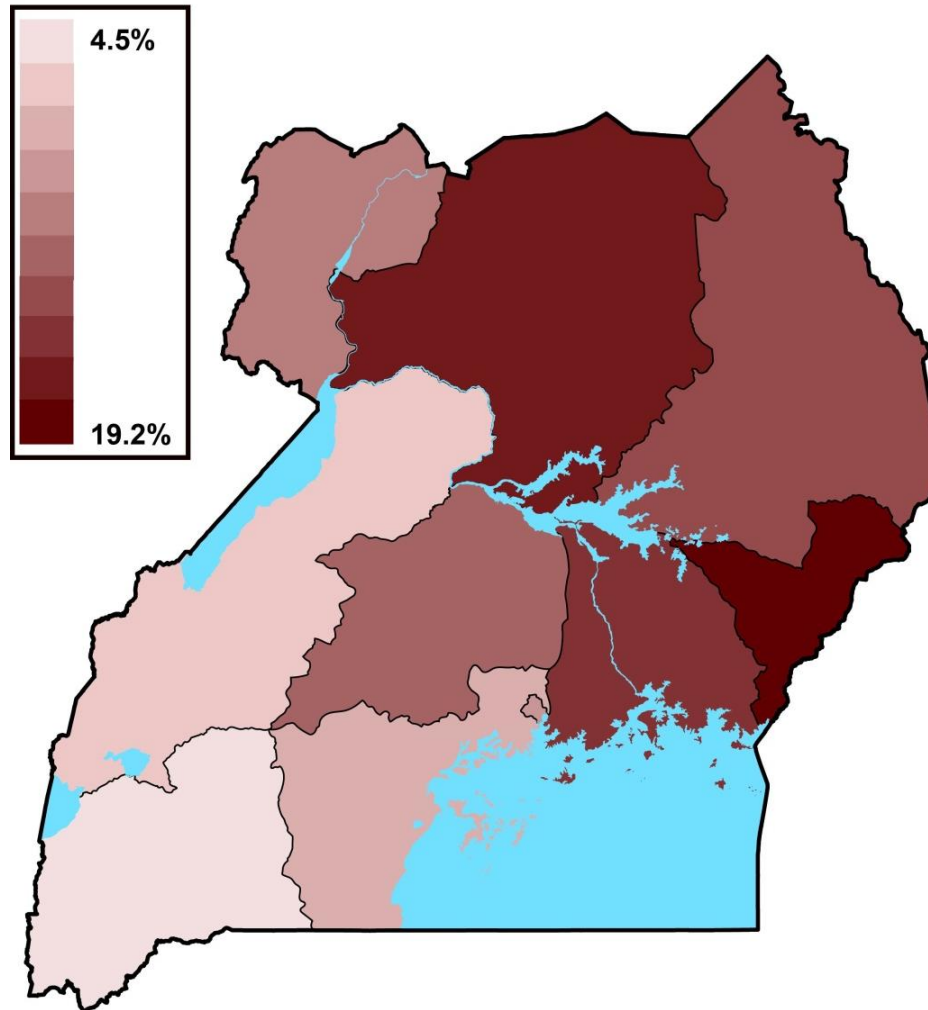
Sickle Cell Trait: Prevalence by Region

Region	Normal	Variant	Trait	Trait (%)	Disease	Disease (%)	TOTAL
Central 1	12187	30	1802	12.80	64	0.45	14083
Central 2	9048	31	1486	13.95	85	0.80	10650
East Central	4911	42	1201	19.24	89	1.43	6243
Kampala	11006	40	1725	13.42	81	0.63	12852
Mid Eastern	3835	35	721	15.52	55	1.18	4646
Mid Northern	9681	121	2359	19.16	153	1.24	12314
Mid Western	10897	31	1358	11.00	59	0.48	12345
North East	3517	30	651	15.36	40	0.94	4238
South Western	12440	16	586	4.48	25	0.19	13067
West Nile	2421	50	394	13.69	13	0.45	2878
Total	79943	426	12283	13.16	664	0.71	93316

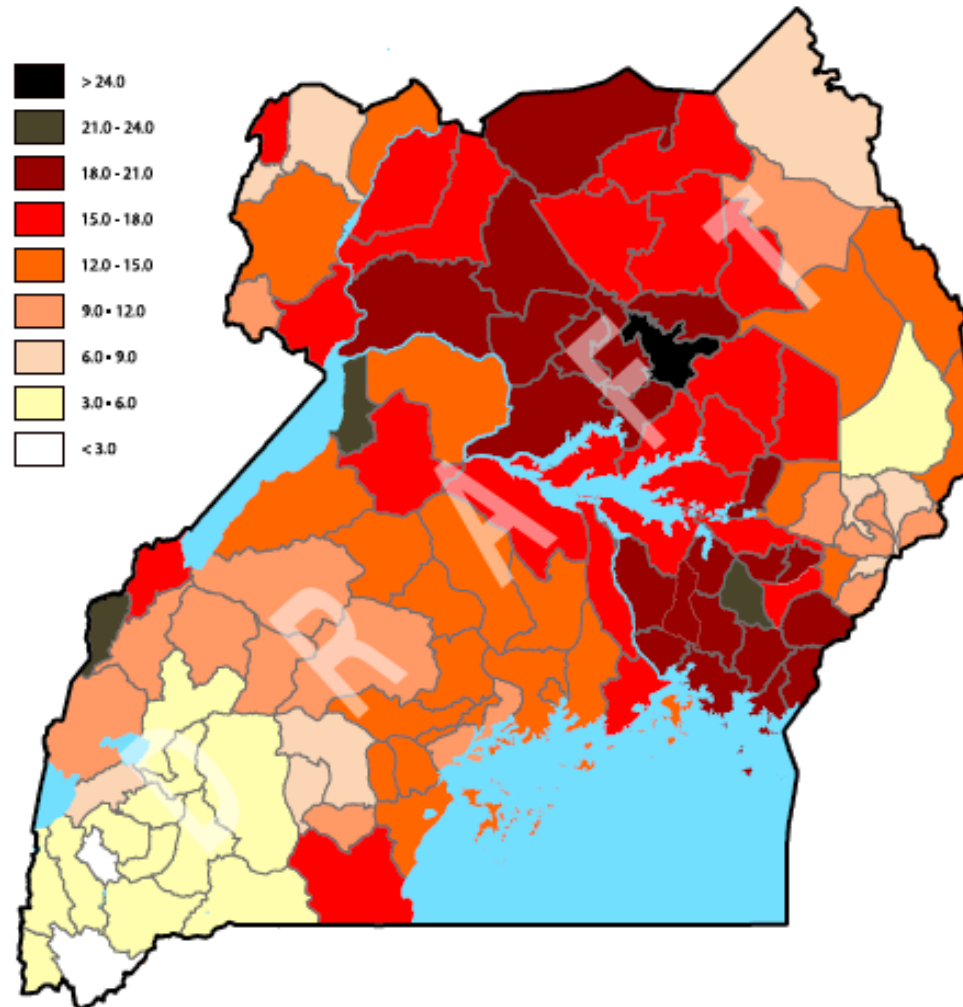
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Uganda Regional Map (US3 Data) Sickle Cell Trait



Uganda District Map (US3 Data) Sickle Cell Trait



Highest Prevalence Districts

49 of the 112 districts have sickle cell trait >15.0%

8 districts have sickle cell trait >20.0%

Bundibugyo 21.9%, Bulisa 22.1%, Alebtong 24.3%

Jinja 18.9%, Tororo 19.5%, Gulu 19.6%, Lira 20.0%

14 districts contain 47% of the sickle cell disease

Kampala, Gulu, Lira, Jinja, Tororo, Luweero, Wakiso

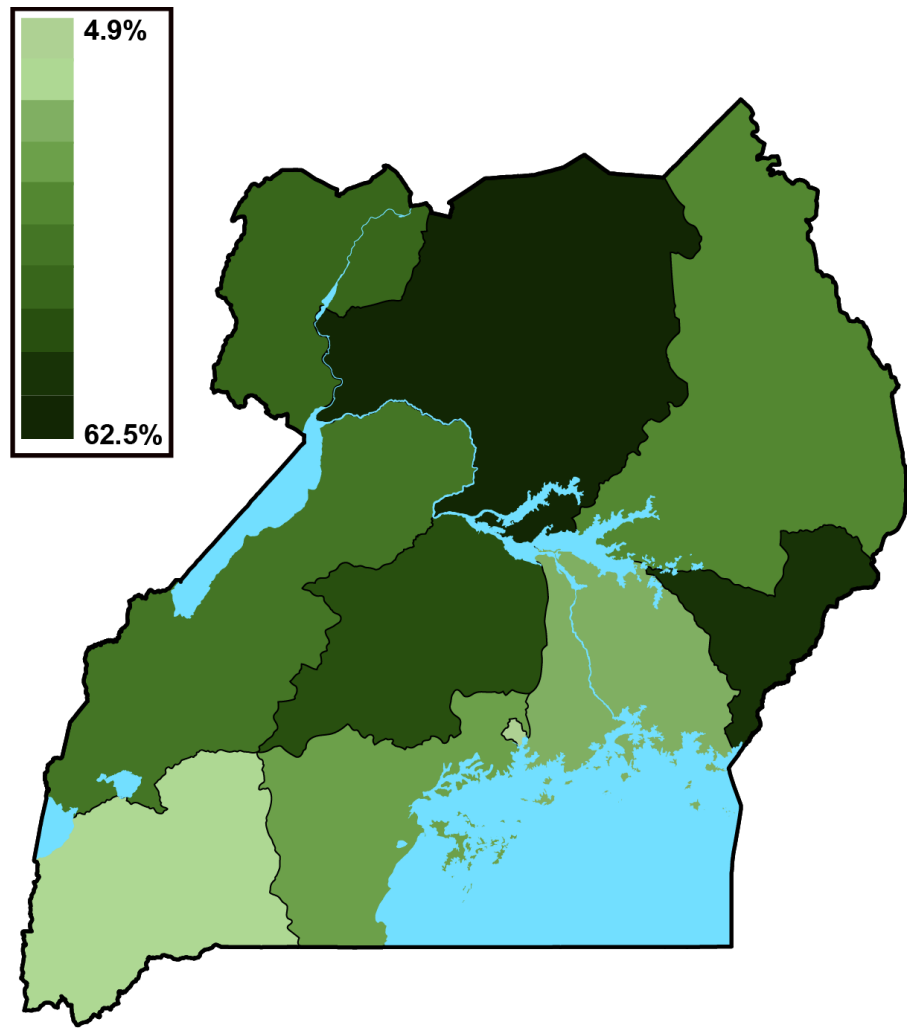
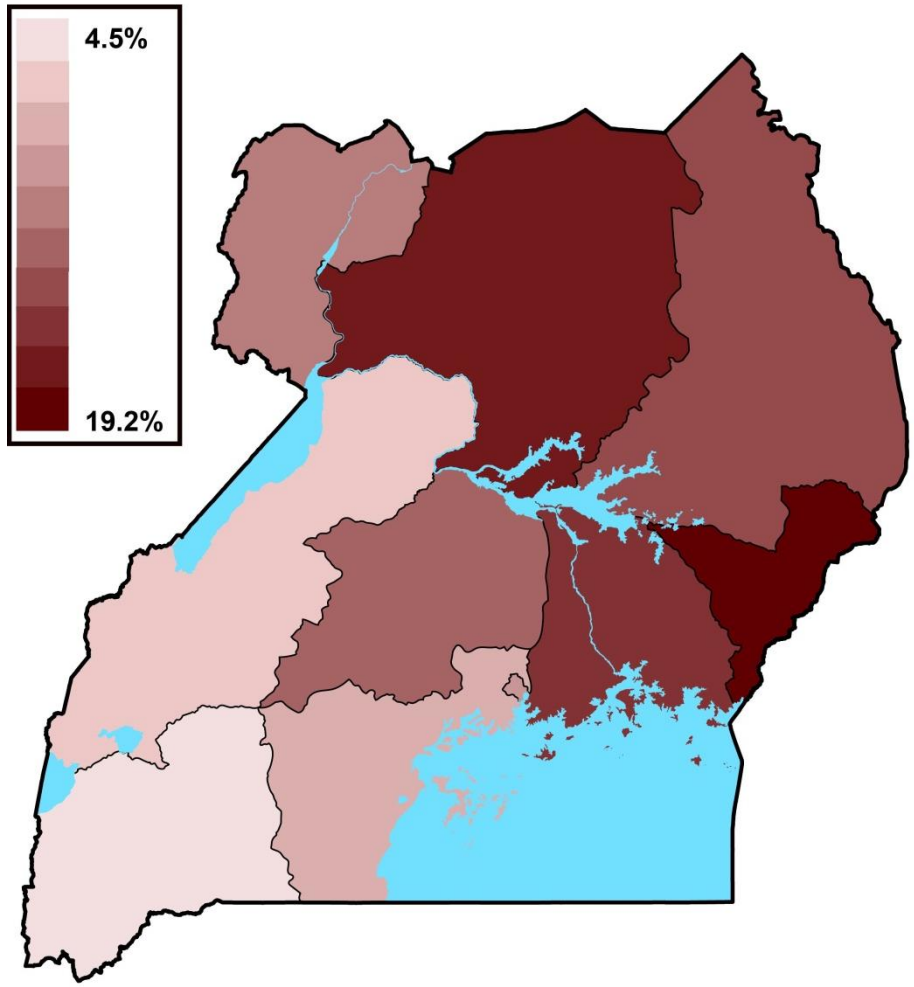
Apac, Iganga, Muyuge, Buikwe, Oyam, Masaka, Masindi

Screening should focus on highest burden regions

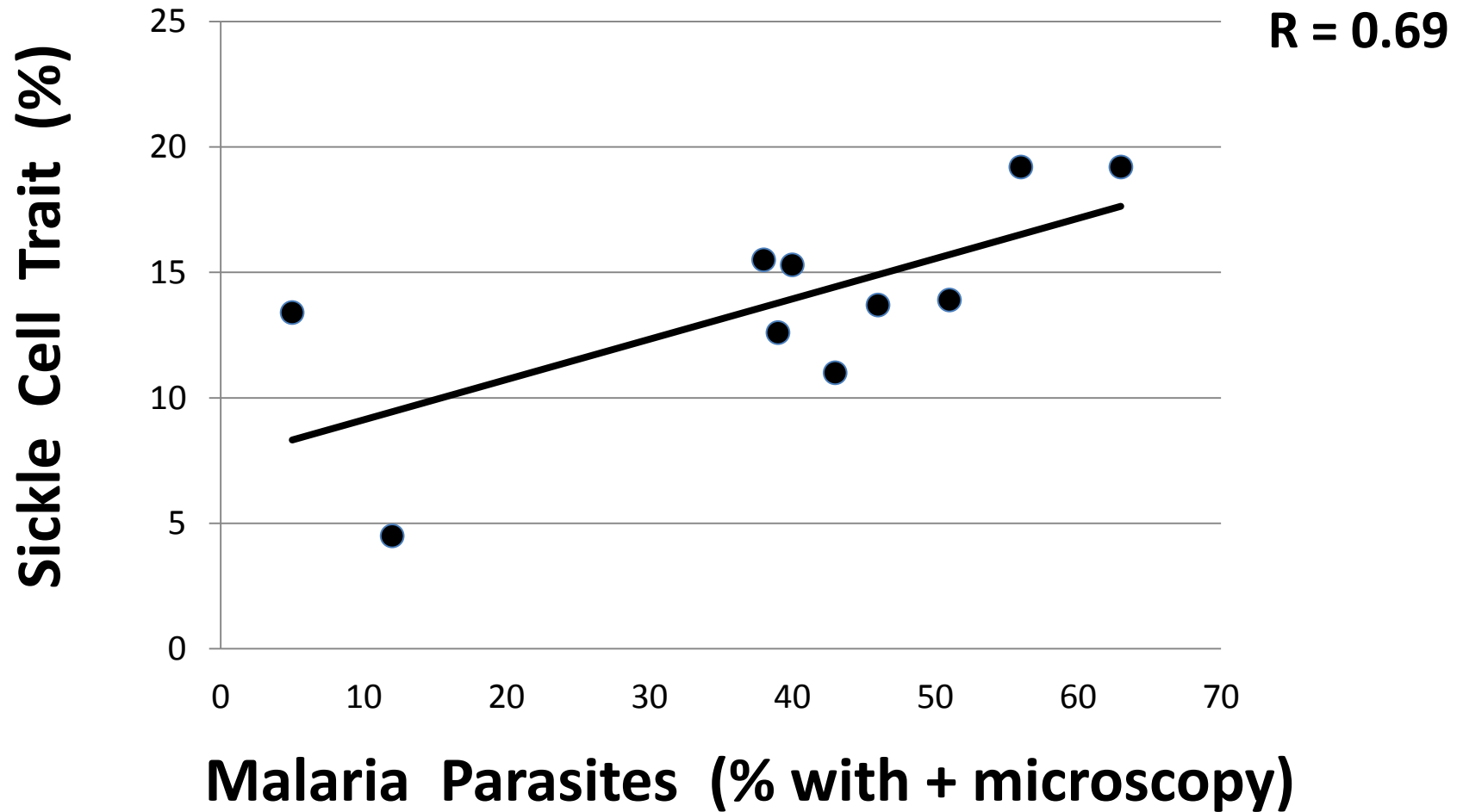
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Uganda Regional Maps (US3 Data) Sickle Cell Trait and Malaria



Malaria Parasites and Sickle Cell Trait



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Sickle Cell Disease: Early Mortality

EID samples are between birth and 18 months of age

Analysis of sickle cell trait and disease by age

Predictions:

Rate of sickle cell trait will increase (malaria survival)

Rate of sickle cell disease will decrease (mortality)

25% Mortality

	Normal (%)	Trait (%)	Disease (%)
Birth – 6.0 months	85.63	13.09	0.76
6.1 – 12.0 months	85.78	13.27	0.64
12.1 – 18.0 months	85.73	13.36	0.57

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Sickle Cell Disease and HIV

All EID samples are from HIV-exposed infants

~5% of the EID samples are HIV-positive

Prediction:

In (+) HIV infants, sickle cell disease is associated with early death

41% Mortality

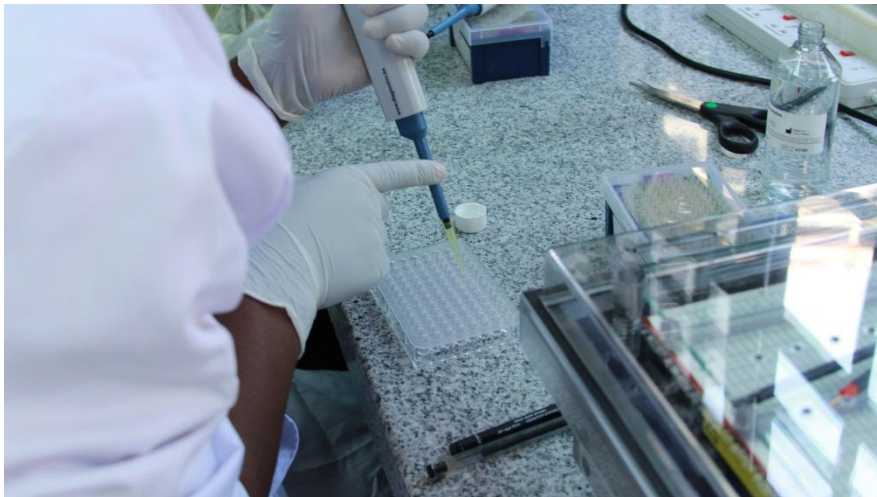
	Normal	Trait	Disease
HIV Negative Infants	86.1%	13.2%	0.73%
HIV Positive Infants	86.6%	13.0%	0.43%

Opportunities to Neonatal Sickle Cell Screening

- Results of the sickle cell prevalence study
- Laboratory capacity built through the study
- Sample and results transport network

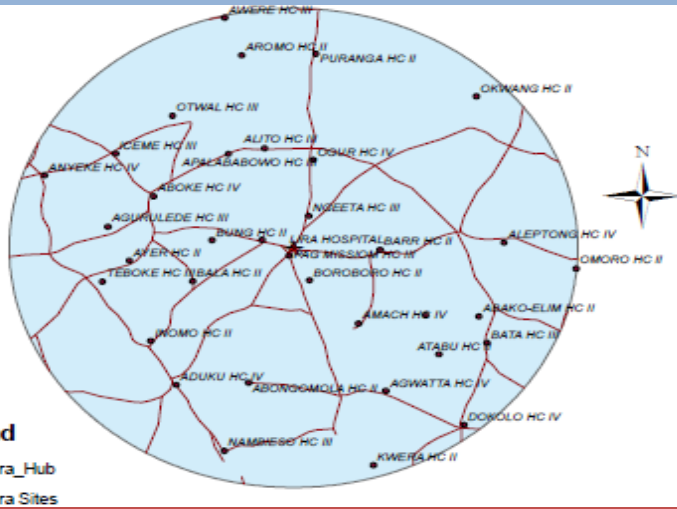
Early Diagnosis

CPHL Sickle Cell Laboratory with Annual Testing Capacity of >600,000 tests

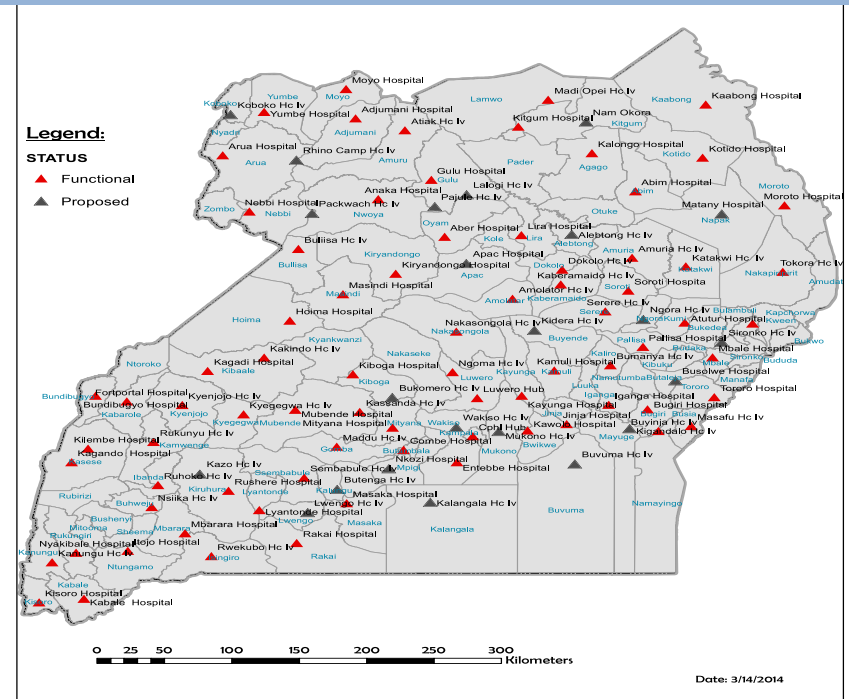


The Hub-based National Specimens and Result Transportation Network

Structure of the hub network



Map showing current Hub Distribution



The bike and rider given to each hub/district, Holly Foundation clinic



- 82 hubs reaching 2400 health facilities with viable laboratories conducting most of the tests for the 30 or so lower facilities in its catchment
- Strategy is to have 100 hubs and strengthen lab services such that lower sites access them thru the NSRTN

Progress to date

District	No. of sites	No. tested
Gulu	42	2158
Lira	31	1781
Kitgum	19	963
Oyam	33	1451
Dokolo	16	67
Jinja	28	1936
Tororo	41	2031
Makerere launch		1803
Eden Church		237
Namasuba College		103
Total	211	12,530

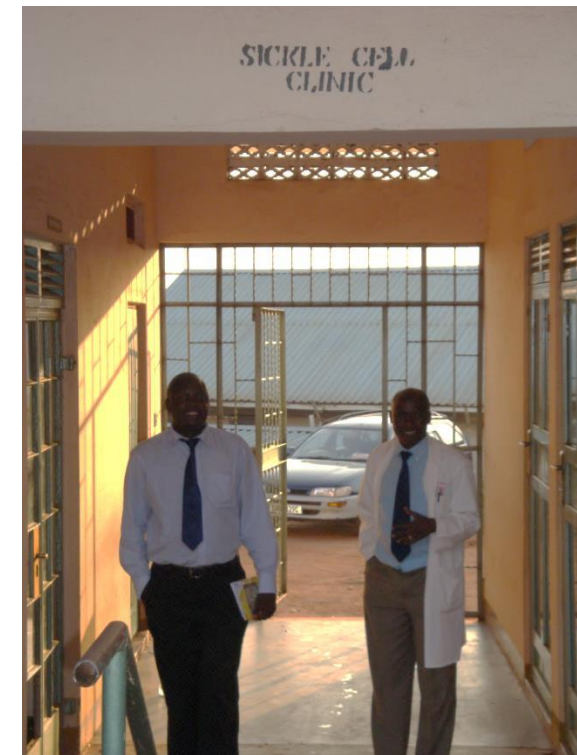
Care and Treatment

Early care and treatment

- Penicillin prophylaxis
- Malaria control and prophylaxis
- PCV (pneumococcal) and other immunizations
- Clinical management
- Health education
- Screening for stroke risk
- Home management

Enroll the baby into sickle cell care

- Dedicated sickle cell clinic days and staff
- Establish routine follow-up
- Establish emergency SCD care plan
- Continued family education



Acknowledgements

- Cincinnati Children's Hospital in the USA
- Dedication and support of the CPHL leadership and laboratory staff
- Makerere University for support of research and educational efforts
- MoH for vision and planning to allow this project to move forward