Leaving no one behind in sleeping sickness elimination: Opportunities & gaps within Uganda’s integrated refugee policy

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Sleeping sickness & forced migration

- Affects mind & body, fatal without treatment
- Outbreaks associated with conflict & forced migrations
- Humanitarian agencies historically important actors
  - MSF treated 30% of cases at epidemic peak
  - MSF 4th largest R&D donor
- All endemic countries host forcibly displaced populations
Sleeping sickness elimination: a changing landscape

Nascent elimination targets & guidelines
• 1st sleeping sickness target in 2012

New technologies & strategies
• 1st sleeping sickness RDT, oral drugs, tsetse control innovations
• Half of cases detected through ‘research’

New actors
• Belgian govt, Gates Fdn, Product Development Partnerships (DNDi & FIND, both part-funded by DFID)

Fewer cases, more displacement
• Natl program staff responsible for all: control / research, refugees / host pop
Forced migration to Uganda

Since 2013:
- 1 million refugees
- 19 sleeping sickness cases in northwest Uganda, including refugees

Promising policy context:
- Refugees served in govt health facilities
- Sleeping sickness RDTs available in govt health facilities

...but challenges...
Programmatic challenges during refugee influx

1. Unbalanced international financial support to government services
   - UNHCR prioritises primary healthcare
   - Little $$ to expand vertical programmes

2. Sleeping sickness coordination staff reluctant to engage humanitarian coordination structures

3. Rapid expansion of health teams → sleeping sickness RDT knowledge & norms lost

4. Difficulties screening for a rare disease through different languages & cultures

In refugee settlements:

- RDTs hardly used → Little surveillance data produced → No cases to prompt suspicion
5. No international guidance on acceptable rate of RDT use for elimination

6. Perceived pressure to demonstrate value for money
   - Program cost to add/keep an RDT facility: $300/a

7. Momentum of original plan:
   - Withdraw surveillance resources (as quickly as possible) in areas judged to have low disease risk

Programmatic outcomes

- Surveillance gaps in some areas densely populated by refugees
- Opinion of refugees: access to sleeping sickness tests better before displacement
Including refugees in disease elimination: challenges observed from a sleeping sickness programme in Uganda

Jennifer J. Palmer, Okello Robert and Freddie Kansiime

Enhanced passive screening and diagnosis for *gambiense* human African trypanosomiasis in north-western Uganda – Moving towards elimination

Charles Wamboga, Enock Matovu, Paul Richard Besseli, Albert Picado, Sylvain Biéler, Joseph Mathu Ndung’u
<table>
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<tr>
<th>Gaps in the evidence base</th>
<th>Gaps in policy work</th>
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<td>How best to serve forcibly-displaced populations in an elimination context?</td>
<td>How to conceptualise the responsibilities of host governments &amp; partners towards refugees during elimination?</td>
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<td>What level of case detection (reach &amp; quality) is needed to verify elimination?</td>
<td>How to support/incentivise host governments &amp; partners to anticipate needs of displaced populations during elimination?</td>
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<td>How best to monitor elimination equity between host &amp; displaced populations?</td>
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**Implications for DFID**

→ Clear governance gap in supporting elimination of HAT (and potentially other NTDs) in fragile states and forcibly displaced populations