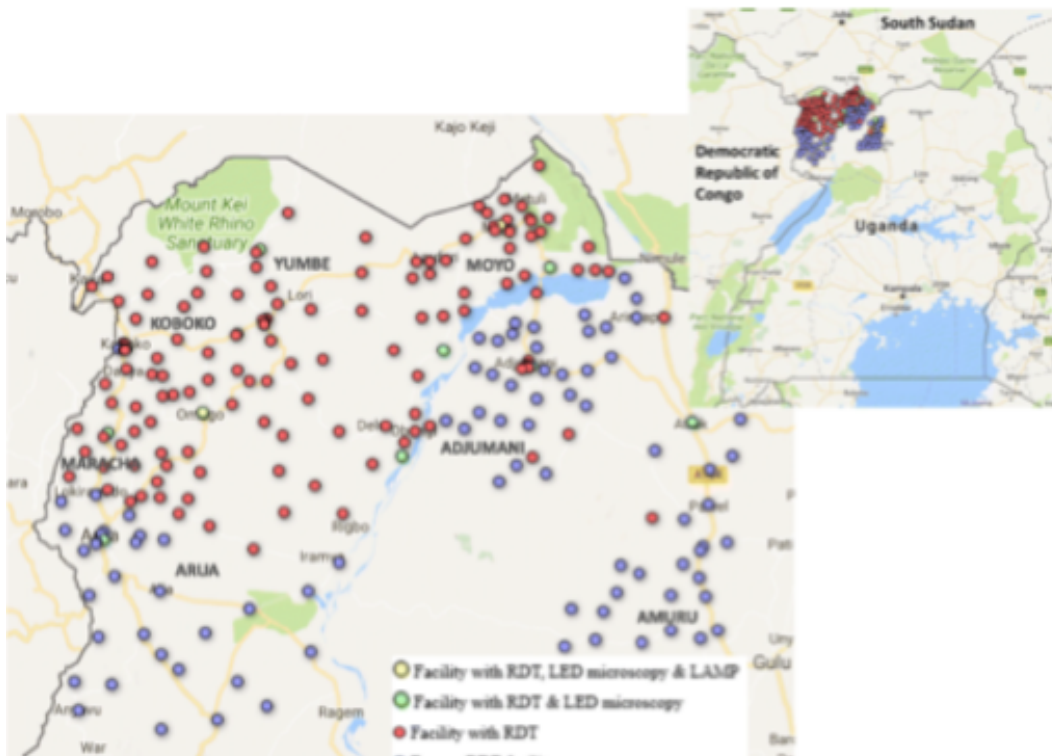


<http://somatosphere.net/2018/05/humanitarian-diagnostics.html>

Humanitarian diagnostics for sleeping sickness in Uganda

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By Jennifer Palmer



Map of sleeping sickness RDT availability (red dots) in the north-western region of Uganda hosting refugees from South Sudan. In 2015, the majority of refugees in this region lived in Adjumani district, where RDTs were selectively withdrawn (blue dots) because the government's surveillance strategy was not identifying cases. Partly this was because of the social complexity of getting the RDTs into use in the context of a humanitarian crisis. Original, interactive online map available at <https://www.finddx.org/ntd/hatprojects/implementation-of-hat-diagnostics/>.

A key impetus for the invention of a Rapid Diagnostic Test (RDT) for sleeping sickness (also known as human African trypanosomiasis or HAT) was the persuasive advocacy for better 'field ready tools' by medical humanitarian agencies such as Médecins Sans Frontières. They were engaged in fighting outbreaks of this disease, which is fatal if untreated, in contexts of weakened health systems and mass displacements during the Central African wars of the 1990s.

When RDTs to screen for sleeping sickness came on to the market in 2013, humanitarian agencies and [global health donors](#) primarily saw their value in terms of their 'lightness'. Because screening tests no longer required electricity, refrigeration and specialised laboratory technicians to standardise reagents, tests could be packed onto motorcycles for health staff to work in much smaller teams to systematically screen villages.

When war broke out in South Sudan at the end of 2013, eventually causing the displacement of more than one million people into Uganda, many within the government and the humanitarian community feared an outbreak would follow. At a national stakeholders meeting, for example, a member of the government's trypanosomiasis control agency suggested, "Refugees who come into the north should not be allowed to go to the hinterlands until they are screened. [...] Those found positive should not be allowed to come in."

Interestingly, in the years since this crisis began, RDTs have largely not been used in Uganda in the ways envisioned by humanitarian agencies. For one thing, today they are more likely to be found in health facilities rather than on the backs of motorbikes. For another, they have tended not to be used in refugee populations much at all.

Partly this relates to the scale of the global epidemic of sleeping sickness which has changed since the urgent pleas for help came from humanitarian agencies in the 1990s. As in most parts of Africa, the disease has so receded in Uganda that it is no longer cost-effective to screen everyone for the disease. Instead, the Ugandan control programme has reorganised activities so that sleeping sickness screening is integrated into the everyday work at government health facilities –something which was only possible with development of the RDT (see [piece by Shona Lee](#)). These government facilities are also the main access point to sleeping sickness diagnostic technology for refugees.

Such a departure from the humanitarian vision of how sleeping sickness RDTs should be used in an emergency also relates to how humanitarian responses have evolved globally. Rather than funding humanitarian agencies to organise flexible but hard-to-sustain mobile teams to bring healthcare to displaced populations, the international community increasingly channels funds into government systems to expand services at static facilities which can serve both local and displaced people. For staff working in Uganda, the idea of an RDT fit well into this sort of humanitarian response because they viewed RDTs as a useful short-cut to having full lab infrastructure. Staff working to rapidly upgrade facilities for the expanded population have said, for example, "we haven't yet got microscopes, our laboratory is not fully ready but we have rapid tests".

But while sleeping sickness RDTs may have solved the problem of complicated laboratory infrastructures which has been particularly acute in this crisis, they did little to simplify the increasingly complex disease control governance arrangements needed to mobilise government health workers to actually use RDTs on refugees. Gaps and disconnects occurred in all parts of the health system required to detect cases of sleeping sickness in this population.

Refugees who were worried about sleeping sickness, for example, complained about how difficult it was for them to explain their symptoms, which should have prompted health workers to use the RDTs. Translators were not always available or helpful. Reflecting political tensions preventing full social integration of refugees into government systems, refugees also wondered if health staff purposely didn't use available RDTs and microscopes on them because staff saw refugees as "enemies". Staff, themselves, felt so overwhelmed by patient needs that this left little time to educate new workers joining the facility on how to use the new sleeping sickness test, particularly the syndromic algorithm and other norms they were expected to adopt along with the technology.

Perhaps most importantly, with few exceptions, government staff managing the sleeping sickness control programme viewed supervising activities in facilities which were part of the humanitarian surge response as outside of their mandate. At the district level, this meant that supervisors rarely visited refugee-serving facilities and tended not to investigate reasons for very low levels of RDT use by health staff in these populations. At the national level, an easier option was simply to withdraw tests from most facilities where the strategy was not working. They switched their focus instead to ensuring quality at higher level 'sentinel surveillance' sites covering bigger populations indirectly. Here laboratory systems may have been better but they were also far away from most refugee settlements.

That government actors chose not to pack sleeping sickness RDTs onto motorbikes in Uganda is of course not a problem. Diagnostic tools will always be used in different ways than originally expected to suit intervention contexts that move on as technologies make their way through research and development pipelines. What is troubling is that this test, with accessibility at the forefront of its design and specifically called for by humanitarian agencies, has remained unavailable to populations most at risk of disease, in one of the biggest humanitarian crises affecting sleeping sickness regions today.

As so many entries in this collection show, the effectiveness of diagnostic technologies is inextricably linked to the social infrastructures surrounding them which make disease detection work. Humanitarian crises are

particularly complex socio-political settings where diagnosis depends on cooperation across both government and humanitarian systems no matter the infrastructural 'short-cuts' new technologies appear to create.

Further details of Uganda's use of sleeping sickness RDTs in refugee populations can be found here:

<https://conflictandhealth.biomedcentral.com/articles/10.1186/s13031-017-0125-x>

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[Diagnostic stories](#) follows the emerging world of devices, instruments, protocols and machines that make up the world of global health diagnostics. Through the telling of stories about specific technological artefacts it traces the rise of diagnosis as a global health concern and offers a critical perspective on the device-focused approach of many attempts to improve diagnostic infrastructure in the Global South. The series is edited by Alice Street.

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