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Clinical trials as disease control? The political economy of sleeping sickness in the Democratic Republic of the Congo (1996–2016)

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ABSTRACT

Human African Trypanosomiasis (HAT), commonly known as sleeping sickness, is closer than ever to being eliminated as a public health problem. The main narratives for the impressive drop in cases allude to drugs discovery and global financing and coordination. They raise questions about the relationship between well-funded international clinical research and much less well-endowed national disease control programmes. They need to be complemented with a solid understanding of how (and why) national programmes that do most of the frontline work are structured and operate. We analyse archives and in-depth interviews with key stakeholders and explore the role the national HAT programme played in the Democratic Republic of the Congo (DRC), a country that consistently accounts for over 60% of HAT cases worldwide. The programme grew strongly between 1996, when it was barely surviving, and 2016. Our political economy lens highlights how the leadership of the programme managed to carve itself substantial autonomy within the health system, forged new international alliances, and used clinical trials and international research to not only improve treatment and diagnosis but also to enhance its under-resourced disease control system. The DRC, a country often described as 'fragile', stands out as having an efficient national HAT programme that made full use of a window of opportunity that arose in the early 2000s when international researchers and donors responded to the ambition to simplify disease control and make HAT treatment more humane. We discuss the sustainability of both the vertical approach embodied in the DRC's national HAT programme and its funding model at a time when the number of HAT cases is at an all-time low and better integration within the health system is urgent. Our study provides insights for collaborations between unevenly-resourced international research efforts and national health programmes.

1. Introduction

The road to eliminating diseases is typically described as requiring both an investment in human and logistical resources for disease control and research on more efficient treatment, diagnosis, and prophylaxis (Dowdle, 1998). In practice, biomedical and clinical research resources are primarily concentrated in high-income countries. In contrast, the diseases that appear the most likely candidates for elimination –including polio, yaws, dracunculiasis and sleeping sickness– are concentrated in low-income countries. In 2018, high-income countries spent more than twice as much money per capita on research and development in health than low-income countries spent on *all* their health expenditures (supplementary material a). The recent history of Human African Trypanosomiasis (HAT) in the Democratic Republic of the Congo (DRC) provides an important and illustrative case for reflecting on the relationship between internationally-led clinical research on infectious diseases and efforts for control and treatment spearheaded by national health authorities.

HAT is closer than ever to being eliminated as a public health problem. The WHO has already certified elimination in Togo and Côte d'Ivoire and has set the goal of zero transmission worldwide by 2030. In 2019, just twenty years after the WHO estimated an all-time high of 340,000 new cases per year, the number of recorded new cases had dropped to an all-time low of 980 cases, mainly in the DRC. Different narratives have been put forward to explain this dramatic evolution. On the one hand, the biomedical and clinical literature has stressed progress in developing new treatments and diagnostics (e.g. Dickie et al., 2020). On the other hand, public health researchers have highlighted a "global enterprise of eradication" –including pan-African commitments to eradicate the tsetse fly (*Glossina* spp., the vector of the disease), the

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international coordination platform set up by the Drugs for Neglected Diseases initiative (DNDi), and the substantial funding provided by the Bill and Melinda Gates Foundation (e.g. Barrett, 2018). These narratives are complementary rather than mutually exclusive. However, to fully explain the current situation, they need to be connected to a third story: the much less frequently documented role of the national actors leading HAT control efforts. This article investigates sleeping sickness control in the DRC between the First Congo War (1996–1997) and 2016. It seeks to understand how its national HAT programme –the *Bureau Central de la Trypanosomiase* (BTC) and its successor, the *Programme National de Lutte contre la Trypanosomiase Humaine Africaine* (PNLTHA) – was structured, why it was structured that way, and how it managed to grow significantly over twenty years, against the background of a challenging context. We show that the programme maintained substantial autonomy vis-à-vis the rest of the Ministry of Health, attracted new resources, made new international allies, and used clinical trials to improve treatment and enhance disease control. We discuss the implications of such experience for disease elimination and the often asymmetrical relationship between clinical research and disease control beyond the case of HAT in the DRC.

The following sections provide a brief overview of HAT control and history. Section three presents our methods and conceptual approach. Section four describes the evolution of HAT control in the DRC since independence, and section five is our main analysis.

2. Background: detecting and treating sleeping sickness

HAT is a terrifying disease. People bitten by haematophagous tsetse flies carrying the *Trypanosoma brucei gambiense*, the protozoan trypanosome parasite that causes the disease, enter a long pauci-symptomatic phase that can last years. Then starts the neurological stage of the disease: it is characterised by symptoms including confusion, poor coordination, numbness, mania, and a disruption of the circadian sleep-wake rhythm that gave the disease its popular name. The parasitic infection of the neural system results in irreversible damage and, if untreated, leads to almost certain death within a few years. A more acute form of the disease caused by the subspecies *T. brucei rhodesiense* exists in East Africa but does not affect the DRC.

The evolution of *gambiense* HAT treatment is well documented in recent literature (e.g. Dickie et al., 2020). Fexinidazole, taken by mouth and authorised in 2018 in the DRC, is recognised as the most effective treatment for both the first and mild second stages of the disease. Two second-stage treatments preceded it: the Nifurtimox-Eflornithine Combination Treatment (NECT), authorised in 2009, and Eflornithine-only treatments, introduced in 1990. For the best part of the 20th Century, however, two drugs that had come to use in colonial times were used against HAT: injections of pentamidine for first-stage cases (which came to use in 1937) and injections of the arsenic-based melarsoprol (discovered in 1949), better known under its trade name Arsobal in the DRC, for second-stage cases. Melarsoprol causes reactive encephalopathy in 5–10% of patients, and 1–5% of patients die from taking it (de Koning, 2020).

The Card Agglutination Tests for Trypanosomiasis (CATT) is used to detect antibodies. It is described as simple, low cost, and reliable, and it is used by all active screening programmes (Bonnet et al., 2015). A microscopic examination (using centrifugation methods) is necessary to confirm the presence of trypanosomes and the disease stage. In the last decade, Rapid Detection Tests (RDT) have further simplified screening.

3. HAT control in historical context

Ford (1971) suggests that HAT was under control in African societies before slave traders and colonists' arrival: the so-called tsetse belt was loosely populated, and tsetse-infested areas were carefully avoided. Slavery and colonisation dramatically affected such equilibrium, and by the end of the 19th Century, outbreaks of sleeping sickness ravaged West, Central, and East Africa. HAT quickly became "the" colonial disease, a significant concern for the colonists and a central enquiry of the allied nascent discipline of tropical medicine (Mertens and Lachenal, 2012; Welburn et al., 2009). HAT justified enterprises of social engineering in the British, Portuguese, and French empires (see the rich literature on this, e.g. Varanda and Théophile, 2019; Webel, 2019). The authorities of the Congo Free State and, later on, the Belgian Congo were among the most invasive and pervasive in their efforts to control the disease (Lyons, 2002). From lazarettos to medical experimentation and severe restrictions of movements, HAT was the justification for interventions in all aspects of life, particularly in the 1920s and 1930s (Steverding, 2008). In 1960, when the Congo regained independence, only 131 new cases were reported (WHO, 2009). Worldwide, endemicity remained low globally until the 1970s, when new HAT epidemics started and gave the 20th Century profile of HAT its infamous U-shape (Fig. 1).

The gradual weakening, and sometimes halt, of HAT control programmes, the reduction in general public health capacities following the economic crises in the 1970s and structural adjustments and recession in the 1980s, environmental concerns that led to a ban of DDT (which had been instrumental in reducing the population of tsetse flies) as well as conflicts in central Africa have all been blamed. The peak of the epidemic was officially reached in 1998. The present article focuses on the institutions, people, and ideas involved in the history that started around that peak and was followed by a rapid reduction in HAT cases.

The literature on HAT is chiefly concerned with the clinical aspects of the disease –the efficacy of new drugs, treatments, tsetse traps– and, to a lesser extent, the social and epidemiological dimensions of HAT control. However, the current and recent organisation of HAT control efforts, including the systems put in place and the people and institutions taking part in HAT control and research, has only gathered limited attention. Seminal historical research, particularly Lyons (2002, on the DRC) and Lachenal (2014, at a broader level), provides in-depth analyses of the politics and economics of HAT research and control in the colonial era. Some work on the DRC also exists on the period between independence and the fall of Mobutu (e.g. Le Ray, 2006), but such extensive research does not exist for the more recent period. The ambition of this paper is to start filling this gap. In doing so, we build on accounts written by the actors of HAT control and research themselves: Le Ray (2006) and, more importantly, Van Nieuwenhove et al. (2001)'s key analysis of control activities and cases in 1989–1998 and Lutumba et al. (2005)'s equally useful description of funding and control in 1993–2003. While centred on explaining the sleeping sickness (epidemiological) situation, these papers do include useful information about the organisation of HAT control and research; our research complements them by putting recent HAT activities in broader historical perspective, extending the time-frame and, importantly, making a novel political-economic analysis concerned with institutional dynamics and key actors. We focus on the period between 1996 –a year marked by the first Congo war but also by a new directorship of the HAT national programme (BCT) – and 2016, the year before we conducted our main field research.

4. Methods

The primary material for writing such history is a series of interviews with key informants. Twenty-one extended interviews were carried out in 2017, in French, mostly in Kinshasa (the rest in Geneva and over the phone). The participants were mostly Congolese public servants and researchers as well as Congolese and foreign experts who have been involved in HAT control and research in the DRC in various leadership capacities: working for DNDi, the Prince Leopold Institute of Tropical Medicine in Antwerp (ITM), the Belgian Embassy, the Swiss Tropical and Public Health Institute (Swiss TPH), and the Foundation for Innovative New Diagnostics (FIND). We also used the transcriptions of ten interviews with key international stakeholders (at the WHO, ITM, FIND, and Swiss TPH) carried out in English in 2015–2016 by colleagues of the Investigating Networks of Zoonosis Innovation research project at the

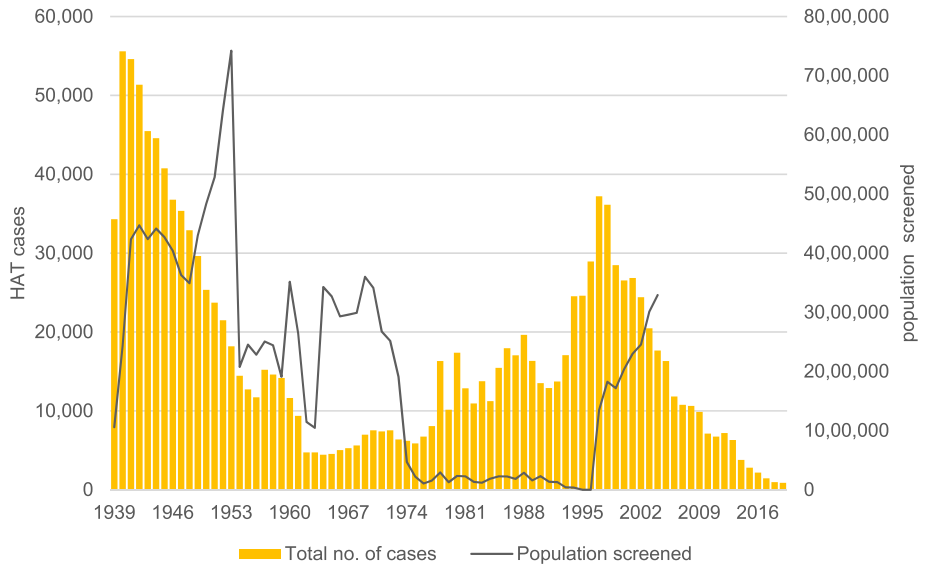

Fig. 1. HAT cases worldwide: 1939–2019 (data: WHO, no screening data available after 2005).

University of Edinburgh (INZI). The interviews are referenced using square brackets. We use deliberately broad categories to preserve the anonymity of our participants: 'HAT', 'national' or 'international' respectively refer to current or past staff members of the national HAT programmes, other national actors (e.g., from other parts of the Ministry of Health), or international stakeholders and researchers. The INZI interviews, all with international actors, are referred to as 'INZI'. The former heads of the national programme are central to our story and have agreed to be identified by name. Supplementary material b provides more details on the researchers' methods and positionality, following the consolidated criteria for reporting qualitative studies (COREQ), and supplementary material c an anonymised list of the interviewees.

Archival documents are few, and the national HAT programme lost many documents while moving to a new building in 2011. We got access to some of the PNLTHA annual reports (2004, 2006, 2007, 2010, 2011, 2014, 2015, and 2016), which occasionally provide information on collaborations and finances, as well as a few other documents (project reports, national strategies). They helped triangulate some of the information and pin down the chronology, key names, and figures. External sources that could help strengthen such triangulation are limited, and this is a limitation to our work: media reporting says little about the organisation of HAT control, and we were not able to access NGO and WHO archives, the most interesting part of which –correspondence and reports submitted to WHO– remained sealed at the time of research. However, elements in the academic literature, especially the actors' accounts mentioned earlier, help with triangulation by revealing some of the HAT general dynamics.

The idea of exploring the potential use of clinical trials in HAT control was suggested to us by then INZI research fellow Michelle Taylor. Joseph Ndung'u, the executive director of FIND, had explained to her during a private discussion and later in an interview in 2013 that FIND's large-scale trials of HAT diagnosis in Uganda made key contributions to HAT control (also see Wamboga et al., 2017). To explore whether a similar scenario might have played out in the DRC and to explore the broader question of the structuring of the national HAT programme, we decided to reconstruct the history of two decades of HAT control. We transcribed the interviews and coded them in reference to the key themes that had emerged during fieldwork (key actors, technologies, funding streams, points of tension and disagreement between actors) before analysing them.

Our interest in this paper was to go beyond a chronological, 'factual' presentation of the findings. To achieve this, we used an analytical lens that borrows from the broad tradition of political economy: we take institutions as endogenous and seek to cast light on how and why they [in this case, HAT control in the DRC] "are structured in particular ways" and survive (Weingast and Wittman, 2008, p. 3). With this general question in mind, we analysed our data using a framework derived from Sparkes et al. (2019). In their paper, they sought to understand when health financing reforms succeed by considering the 'politics' of five categories: interest groups (key stakeholders), bureaucracy (intra--government relationships), budget (funding mechanism), leadership (leaders' commitments and priorities), and beneficiaries. Our research question was different from theirs: the evolution of DRC's HAT control programme is politics in the sense of navigating different stakeholders' views and interests, but it is often less so in the sense of law-making and (often antagonistic) public debates. Opposition is likely less staunch and visible –or maybe just more subtle– in our case: the continuation of longstanding health programmes usually does not trigger the same passionate arguments as political reforms. Sparkes et al. (2019)'s approach was nevertheless useful to understand how the fast growth of the DRC's HAT control programme, which was far from being an expected development in the mid-1990s, is related to dynamics and windows of opportunity at different levels. Importantly for us, their framework starts from a national perspective, looks at finances, and stresses the "connectedness of technical and political processes".

5. HAT control in the DRC

The post-independence epidemiology of HAT in the DRC can be divided into three periods (Fig. 2): relative stability until the 1980s, a peak in the 1990s, and then a sharp decrease in the number of cases. The last period, which is our main focus, is better understood after a brief presentation of the first two periods.

5.1. HAT control under mobutu (1964–1989)

The BCT was created in 1968. It reported directly to the President of the Republic who had been allegedly lobbied to establish a HAT control unit in the country by Fometro (*Fond Médical Tropical*) (Burke, 1971), a Belgian NGO created in 1964 by tropical doctors and researchers to provide logistical support to HAT control (Le Ray, 2006).

The BCT's general approach of HAT control was not dissimilar to both colonial and present-day approaches. Besides the head office located in Kinshasa, regional coordination units were set up in areas of high HAT endemicity, namely the West and Central parts of the country

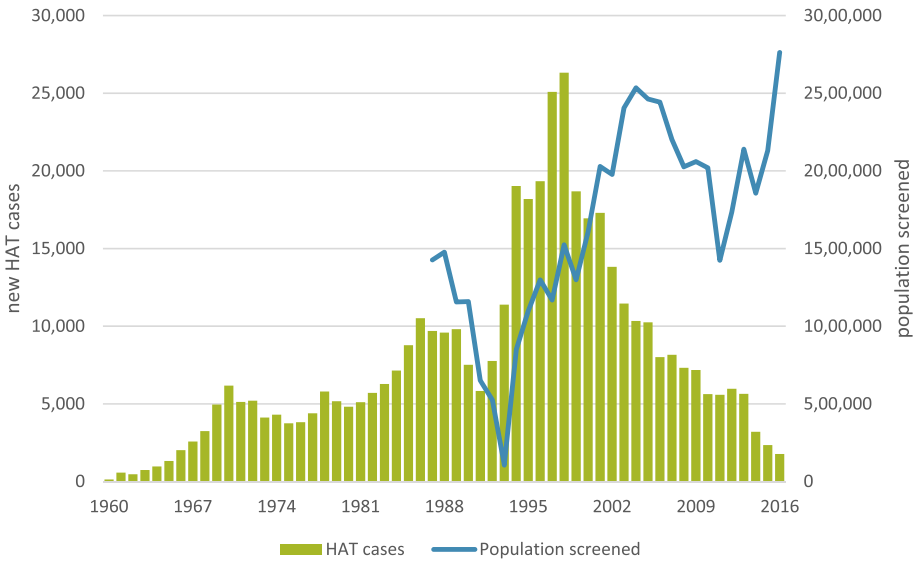

Fig. 2. HAT cases and population screened in the DRC (1960–2016) (source: PNLTHA annual reports).

(Kongo Central, Maniema, and the former provinces of Bandundu, Equateur, and the Kasais). They organised a network of specialised units attached to selected hospitals and health centres and tasked with treatment, passive screening, and extensive diagnosis. In addition, Fometro and the BCT set up mobile teams that could examine 55,000–66,000 people per year in villages of the high- and medium-risk HAT regions they sought to visit yearly (PNLTHA annual report, 2014; p. 10). They were directly inspired by the mobile teams used to control endemic diseases in colonial times (Van Nieuwenhove et al., 2001) and remain a central part of present-day HAT strategies. Finally, the BCT staff also acted on vector control by destroying tsetse flies' environment using insecticide and, more recently, traps.

Initially well-endowed, the BCT saw its staff salaries decrease by 75% in the 1980s (as in other Congolese State services) while shortages in state-supplied drugs became more frequent. As a result, the BCT's reliance on Belgian funding increased, and the boundaries with Fometro blurred totally. In the words of a HAT doctor: "we all had a double hat, Fometro and BCT, at the same time […] Fometro supported 90% of HAT control in the 1980s" [HAT, 4]. Despite these difficulties, the bureau still had 25 fully operational mobile units in the mid-1980s (Van Nieuwenhove et al., 2001).

5.2. HAT control in crisis (1990–1998)

The discontinuation of Belgian bilateral cooperation with Zaire in 1990 –as a sanction against the regime of Mobutu accused of brutal killings at the university campus of Lubumbashi– led to further financial shortfalls for the BCT. The number of mobile teams reached an all-time low of ten functional units in 1991–1993 (Lutumba et al. (2005); four in 1992 according to Van Nieuwenhove et al. (2001)) and the number of people screened fell (Fig. 2). Even then, the number of recorded cases kept growing, especially in Bandundu and Equateur, where HAT reached epidemic levels. Van Nieuwenhove (1992) estimated that the actual number of DRC cases in 1992 was likely five to ten times higher than the official figure.

While the collapse of Belgo-Zairian relations –and, later on, the First (1996–1997) and Second (1998–2003) Congo wars– undoubtedly had dire consequences on HAT control, the epidemic had been in the making for at least ten years. Cases started rising in the early 1980s, and field reports mentioned diminishing screening activities and resurging colonial-era hotspots throughout that decade (Janssens and Burke, 1992). The situation only deteriorated during the 1990s. Adding to an already catastrophic situation, Hoechst Marion Roussel, the only producer of eflornithine globally, stopped producing the drug in 1995, claiming it was not profitable enough.

5.3. The 'miracle' years (1999–2016)

After reaching a peak in 1998, HAT cases started decreasing sharply. Our interviewees often mentioned the key role of drugs development and international support, as, for instance, this international researcher:

> "When we managed to raise international awareness, when we managed to get funding, when we managed to put researchers on it, it went very quickly." [international, 18]

Indeed, all our interviewees conveyed a strong sense of acceleration of HAT activities from the early 2000s, and it is not hard to see why. The BCT survived through limited humanitarian support in the early 1990s (via Lubinga Kasai, a local organisation supported by Caritas Germany, and via Belgian humanitarian aid from 1993). It gradually recovered more support from European and Belgian aid in 1995 and 1997 respectively. By the early 2000s, the international HAT scene changed with the emergence of new players such as DNDi, which was set up in 2003 using seed funding from *Médecins Sans Frontières* (MSF)'s Nobel Peace Prize (and in collaboration with tropical disease research institutes worldwide). Two years earlier, the well-endowed Bill and Melinda Gates foundation had signalled its interest in HAT and they would eventually contribute to DNDi funding. DNDi would prove instrumental in funding research on new HAT treatments such as NECT and later fexinidazole.

There is no question that new drugs and funding contributed to the quasi elimination of HAT today. Still, it is also important to note that not only did the decrease in the number of cases started slightly ahead of this international mobilisation (see Fig. 2), but it was also not before 2008 that a new, effective, and non-lethal treatment to second-stage HAT, NECT, was launched and provided free of charge by Sanofi. The production of eflornithine had resumed in 2001, after MSF's successful lobby of Sanofi-Aventis, the merger of various pharmaceutical companies, including Hoechst Marion Roussel. However, as Fig. 3 shows, it is almost exclusively using colonial-era drugs that the Congolese HAT staff treated patients during the spectacular fall in the number of HAT cases between 1998 and 2007.

Most interviewees, and even more so those working close to the field, stressed the need to pay attention to the crucial role played by the national HAT programme, which had started taking a new direction in 1996 with its new director, Constantin Miaka Mia Bilenge. Indeed, it was

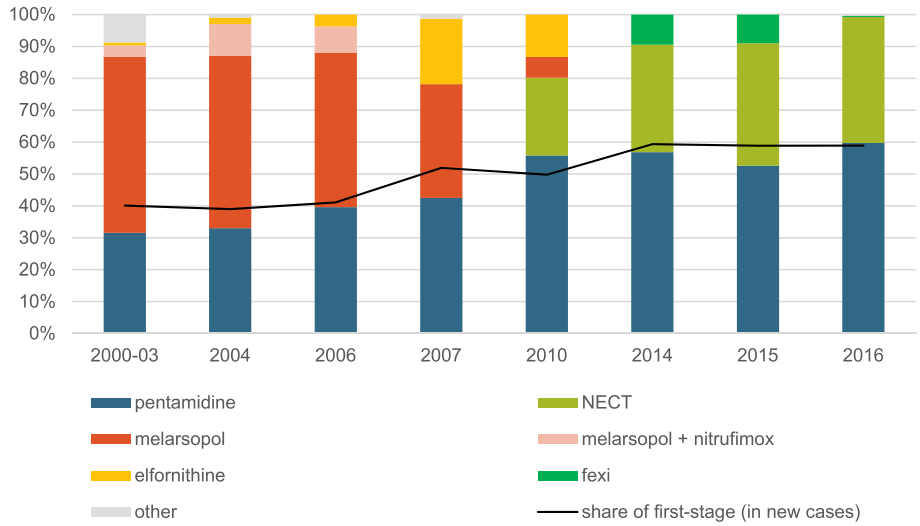

Fig. 3. Share of treatments administered under the BCT/PNLTHA, with ratio of first-stage cases among new cases. Source: PLNTHA annual report and Lutumba et al. (2005) for 2000–03.

not long before national and international actors of HAT would look up to the programme –in the words of a senior WHO official: "the one single country where there was real control going on [by the HAT national programme] was [DR] Congo" [INZI, 2]. In the next section, we use a political economy lens to cast light on this success.

6. Analysis

This section is structured following the political economy dimensions of Sparkes et al. (2019)'s framework (with 'beneficiary politics' discussed under 'leadership politics').

6.1. *Leadership politics: enter the champions*

The recent history of HAT control in the DRC, especially the years 1996–2012, was crucially shaped by a trio of doctors who led the national programme. It is, in part, the story of a strong commitment of leaders (Sparkes et al., 2019), people who Shiffman and Smith (2007) call 'champions for the cause': Miaka, who was director until 2003; Victor Kande Betu Ku Meso, who joined Miaka in 1997 as head of programmes and was the director in 2003–2012; and Pascal Lutumba who was made head of research and lab by Miaka in 1998 and retained this position until 2011. Together, they had both political connections and considerable field experience and credentials. Miaka came to the position as a former advisor at the Ministry of health. Kande was previously the chief-doctor of the then North Ubangi health district, where HAT is highly endemic, while Lutumba was the HAT coordinator in Kasai.

They shared with many of their staff members a deep commitment to fighting HAT, which emerged clearly during the interviews (also see Falisse et al., 2020). Such motivation seems in part related to the vertical, 'small community', nature of the programme (Falisse et al., 2022), and the nature of HAT work, especially when melarsoprol was the only available treatment option for second-stage cases. In 2007, the last year when melarsoprol was still in common usage (36% of cases), 62 patients still died from encephalitis caused by the drug –43% of the HAT-related deaths recorded that year. Kande recalled his experience, which echoed other interviewees':

> "I saw how sleeping sickness was destroying people. You see a person becoming like a pig –I am sorry for the word– totally destroyed. […] The nurse I worked with tested positive […] we had to treat him with Arsobal. He reacted to it and died. When I saw my nurse die, it was a shock, and I told myself I need to do something."

It is at this level that the 'beneficiary politics' of our framework is mainly manifested: patients' influence was not mentioned much in our interviews. Still, the sheer fear of melarsoprol, shared by the population and HAT workers alike, is key to understand the drive to improve screening and treatment.

The trio operated in a difficult context marked by wars that hampered HAT control activities in the field. Even after the wars, political turbulence persisted. Nevertheless, and despite serving under no fewer than three Presidents of the Republic and ten Ministers of Health in 1996–2012, the programme appeared relatively unaffected by national politics and the trio generally free from substantial top-level political interference. The BCT, which had been put under the authority of the Ministry of Health in 1975, was maintained by Presidents Laurent-Désiré and Joseph Kabila.

6.2. *Bureaucracy politics: carving autonomy*

In 2002, as the Sun City peace agreement was finally bringing some stability to the country, the Ministry of Health, whose general secretary ad interim was Miaka, started enacting a series of long overdue health systems reforms, among which the creation of a series of new vertical programmes (e.g., for tuberculosis, leprosy, onchocerciasis). It decreed the BCT to be turned into full-fledged vertical programme, the PNLTHA. Our interviewees stressed that the severity of the HAT situation but also the important growth of HAT-related activities justified such promotion. The move was apparently unopposed, but it is also clear from our interviews that it re-affirmed the primacy of the national coordination structure vis-à-vis other HAT actors. As a former HAT cadre put it:

> "NGOs cannot deal directly with Belgium, they have to deal with us, in this structure –so the reports should not be sent to Belgium, they can be sent to us, because we are the ones who give an opinion. This is how the PNLTHA was set up." [HAT, 4]

In practice, the main structure of the BCT (which was already commonly referred to as a programme) was kept and reinforced, among others with the creation of divisions for training and epidemiological surveillance. As the BCT, the PNLTHA kept enjoying considerable administrative and financial autonomy. "If you ask about HAT at the Ministry, you will be sent to the programme because all the technical and financial aspects are managed by our director" explained a PNLTHA civil servant [HAT, 5]. Such autonomy is at least partly explained by the fact that the programme was not receiving substantial funding from the State and by the key role played by Miaka, who was described by a

PNLTHA cadre as "a determined visionary and diplomat" [HAT, 12]. As General Secretary –head of all vertical programmes– ad interim between 2000 and 2003 and then formally from 2003 to 2007, he was one of the top decision-makers at the Ministry and could steer the PNLTHA through bureaucracy and the political context. As a former senior civil servant of the PNLTHA explained; "he acted as General Secretary, he could take care of every problem [at the PNLTHA], and nobody could oppose him" [HAT, 17]. His position and influence allowed him to protect from interference the PNLTHA, a programme he helped creating and which he formally remained an advisor of until his death in 2014.

Internally, the trio was described as charismatic by our (necessarily neither neutral nor objective) interviewees. They gained respect and legitimacy by supporting their staff's intellectual and technical development (Falisse et al., 2022). Lutumba was particularly instrumental in this regard; in 2005 he finished a PhD at the Free University of Brussels (ULB), after training at the ITM –one of the "key repositories of HAT knowledge in the world" [HAT, 4]– and was also affiliated with the University of Kinshasa and the National Institute for Biological Research (INRB). These connections came in handy to push for the training of a small but influential number of Congolese staff at masters, doctoral and post-doctoral levels [national, 13]. They would become the next generation of Congolese HAT experts.

The stability and autonomy of the BTC/PNLTHA allowed the trio considerable room for setting their own strategy, such as in their first years when they decided to focus on three key areas [HAT, 3 & 4]: (1) epidemiology and cartography of the disease; (2) the social perception of HAT treatment (the fear induced by melarsoprol); and (3) the use of CATT for screening. CATT is a good example of how the trio used its autonomy and authority to get past stumbling blocks. It was not in use in the DRC despite having been solidly established as a diagnostic approach from the late 1970s (Magnus et al., 1978). The exact reason is not entirely clear; it seems related to the Congolese medical establishment's fear of new medical technology and drugs [HAT, 17], field teams unwilling to change well-established practices, but also to diverging HAT schools that promoted different tests (Welburn et al., 1999). As Lutumba put it: "at that time, all the HAT experts in the world would fit into one classroom, and there were at least five or six groups that had totally divergent opinions" –or to use the less diplomatic wording of one of the lead researchers of HAT at the time [international, 18]:

> "There weren't a lot of scientific certainties [in the 1990s] and so it was really attitudes, approaches were dictated by expert opinions, and there's some good in expert opinions too … but when there's not the evidence on which they're based, it was ego wars, in fact, it's big mouths that dominated the picture."

Miaka solved the CATT issue by imposing its roll-out in the main BCT project of the mid-1990s, a HAT control project in the provinces of Kasai and Maniema funded by the 1995–1997 European Commission humanitarian support to the health sector [HAT, 4].

6.3. *Interest group politics: old and new coalitions in a new international context*

The international context of 1998–2016 was more favourable for leading HAT-related activities than the early 1990s but it is also useful to stress that the trio was also apt at exploiting funding and partnership opportunities. In the very late 1990s, HAT started garnering significant attention worldwide thanks to the joined efforts of a new generation of funders, researchers, NGOs, and practitioners. The ITM organised an international conference fittingly titled "Sleeping Sickness Rediscovered" in Antwerp in December 1998 (Welburn et al., 1999). Another international conference followed, this time in Mombasa, in 1999.

6.3.1. *Pushing for opportunities – finding new partners*

The Mombasa conference is described as a game-changer in many of our interviews. It is when the trio indeed became part of a global policy community. At the BCT, Miaka and his colleagues were acutely aware of the need to find partners to extend their activities and develop better treatments [international, 2]; hence, Kande pleaded with the scientific community to provide an alternative to melarsoprol, which "is arsenic" and with which the BCT had "50% relapse rates in Kasai". At the conference, Miaka and Kande met Christian Burri, from the Swiss Tropical Institute (STI, now Swiss TPH). He was one of the few researchers working on a new HAT treatment: a more effective 10-day melarsoprol regimen. Burri needed five hundred patients for his study, leaving him with two obvious field sites: Angola or the DRC. He described how Miaka convinced him to move his study, which had already started in Angola, to the DRC:

> "*He said to me:* 'What are you doing in Angola? Why are you trying to get killed there? You must come to Congo.' [Angola was in the middle of a civil war]
>
> *I said*: 'You must be crazy.' [the DRC was also in the middle of a war]
>
> *And he said*: 'I'll organise a trip for you, and you will see that Congo is way easier.'
>
> He helped us very, very, much from the inside, with a lot of practical assistance. And then, also with Dr Kande, we learned how to deal with these things [organise a trial]. I basically transformed the Impamel Angola study into a DRC study. We had a lot of discussions on how things can be done and integrated into the system. It was a real partnership." [INZI, 1]

In 2000, Burri arrived in the DRC for the Impamel II study (Schmid et al., 2005); it was the beginning of a new series of clinical trials in the country (see section 5.4), all skilfully negotiated by the BCT/PNLTHA directorate. We identified fifteen in 2000–2016 (see supplementary material d), led by various partners, including the University of North Carolina in Chapel Hill, the University of Geneva, and FIND and DNDi (both created in 2003). DNDi soon opened a permanent bureau in the DRC, and its staff described part of their mission as "directing newcomers to the PNLTHA". The Bill and Melinda Gates Foundation soon became a key funder of FIND, DNDi, and the ITM. It funded the development of diagnostics (RDTs, THA lamp – a new molecular test), treatment (DB 287, NECT), and even vector control (tiny targets, with the Liverpool School of Tropical Medicine).

6.3.2. *And strengthening cooperation with older partners*

These resources were primarily directed to research, but what the BCT/PNLTHA needed, first and foremost, was resources for disease control. Public funding remained extremely limited and primarily dedicated to the civil servant's basic salaries –and even these salaries had to be topped up by partners. At the PNLTHA, a civil servant interviewed in 2017 explained:

> "Since 2000, I have only received the civil servant's fee [*frais de fonctionnaire*] once, four years ago, only once, and then once for the intensive work there that we were doing. It was two or three years ago. That's all." [HAT, 5]

With a few exceptions, such as the humanitarian project funded by the European Commission in the mid-1990s, Belgium's public funding still provided the lion's share of HAT control funding throughout our period of interest.

In 1997, the Belgian cooperation agreed to resume HAT funding. Congolese institutions remained, however, untrusted by the Belgian authorities, and the funding was channelled through Belgian NGOs: Fometro in Kinshasa, Maniema, and the then provinces of Bandundu and the two Kasai (as well as the two Kivu, where the disease is almost inexistent); the Catholic NGO Memisa (*Medische Missie Samenwerking*) in North Equateur; and MSF in South Equateur (where it effectively

coordinated HAT control activities under the BCT). A technical advisor of the Belgian Technical Cooperation's (Belgium's state development agency, now known as *Enabel*) was sent to the BCT to support its re-development. He facilitated discussions for direct Belgian support to the BCT to resume, which happened in 2000 with a new 3-year EUR 7.5-million "project to support the fight against HAT". The support reportedly covered between a tenth and half the budget necessary for HAT control [international, 14]. In 2001, six of the seven endemic areas of the country had operational coordination structures with dedicated mobile teams (BCT annual report, 2001). A new technical advisor was also sent to the BCT and stayed until 2013 as two more Belgium-funded HAT projects with a similar design directly supported the PNLTHA in 2003–2008 (EUR 12.4 million) and 2009–2011.

Together with the WHO, the Belgian Technical Cooperation also played a more political role; for instance, by supporting the BCT's development and publication of the 2001 "Policy Statement on the fight against HAT in the DRC" (*Déclaration de la Politique de Lutte contre la trpanosomiase humaine africaine en République Démocratique du Congo*), which prefigured a series of strategic plans for HAT control, as well as a National HAT Forum (the Forum Trypanosomiase, FOTRY) gathering all partners. The WHO and MSF were also crucial in guaranteeing the purchase of eflornithine, some of which went to the DRC, alongside CATT, in direct response to the BCT's difficulty to procure drugs and tests [HAT, 4].

The all-too-important Belgian support was not something to be taken for granted. Belgian and Congolese interviewees explained how Miaka and Kande used their network in Brussels and their relationship with the Belgian embassy to lobby Belgian authorities and thwart cuts threats. In October 2003, they managed to put a visit of the PNLTHA on the agenda of Louis Michel, then Minister of Foreign Affairs, and "twenty or thirty MPs" who were officially visiting the DRC to strengthen Belgian-Congolese relations. The next year, a report of the Belgian Senate (3–254/1) on support to the DRC explicitly mentioned HAT support. However, our interviewees stressed that Belgium's and the Belgian embassy's many –and, therefore, competing– priorities in the DRC, including in the health sector where the HIV/AIDS pandemic was raging, necessitated repeated lobbying throughout the 2000s.

6.4. Budget politics: trials as disease control

With the Belgian funding insufficient to cover all control activities and the Congolese State funding only covering a fraction of salaries, the PNLTHA leaders used research activities, particularly clinical trials, to generate resources to develop control activities and strengthen the PNLTHA.

6.4.1. Instrumental use of research activities

Three approaches can be identified, all hinged on the awareness that "studies not only require scientific and intellectual work that can provide us [the PNLTHA] with solutions, but they also require logistics" [HAT, 4].

Firstly, research was used to improve infrastructure, especially in treatment centres and laboratories. In the Congolese context, clinical trials typically require a substantial upgrading of infrastructure to international standards, including a reliable energy source, below-20- or −70-degree freezers, and other laboratory equipment. Such infrastructure was then also used for control and treatment. As a PNLTHA senior civil servant put it: "if control doesn't work well, you may well splash money on research, you won't get any results –everything is linked […] those who do research cannot go without control, and they need to check that control goes well" [HAT, 9]. In a recent article, Mbo et al. (2020) provide a more comprehensive list of the various in-good and in-cash contributions of research to the PNLTHA. As did our interviewees, they explain that the support also came in the form of training and strengthening capacities –and credit the HAT trials with the set-up of new ethics committees in the DRC.

Secondly, screening and treatment trials required patients, and the PNLTHA 'had' the patients, or rather the ability to find them. As HAT control efforts improved in the 2000s and HAT regressed to low endemicity levels, finding patients became difficult and was especially demanding on the PLNTHA resources. The approach was then to ask research institutions to cover the costs of finding the patients their studies required. As Kande explained:

> "I even had an official document at the time. It stated: 'if you come, you must participate in the purchase of CATTs. You tell your sample –I will have 200 patients. To have 200 patients, you have to examine 1 million people, so give me 1 million CATTs.' We succeeded, and today they [research teams] do this spontaneously, but at that time … For me, it was a way to get around the State's lack of funding, because not everything could be on Belgium's shoulders."

At first, research partners were reluctant, but the strategy eventually worked. It did not necessarily involve directly paying the government, which research institutes were often wary of doing. It typically involved contributing to the PNLTHA by covering the costs of vehicles, fuel, and salary top-ups for mobile teams. Interviewees were quick to point out that actors such as DNDi or FIND started with research but then actively supported control "DNDi finances 10 of our 30 mobile units […and] FIND has a big screening project" [international, 7]. DNDi representatives explained that "control" equipment and PLNTHA salaries (top-ups) are essential to good research.

Thirdly, the PNLTHA fully played its coordination role and dispatched research to the regions that needed it most. Kande explained: "for example, when we started with the NECT treatment trial, I said: 'I have huge problems with relapses in Kasai, more than 50% of relapses [after melarsoprol treatment], so you go there'".

Towards the end of the 2000s, it was clear that, as a PNLTHA interviewee put it, "PNLTHA needs to have research, without research there is no effective control" [HAT, 9].

6.4.2. … And its limitations

In 2010, however, the structure built by Miaka and Kande was put to the test. Following the European Union's recommendation that member states focus their development assistance on fewer sectors, Belgian State aid to the DRC's health sector stopped. The PNLTHA did not have a backup plan, and the memory of the 1990 withdrawal of Belgian aid was in all minds. Eventually, the director of ITM –a world-leading institution on HAT research and control whose very creation in 1906 was intimately related to the disease (Mertens and Lachenal, 2012)– weighed in: financial resources existed, and albeit money could not go through the Embassy or the Belgian Technical Cooperation, funding activities via the ITM remained possible [international, 14]. A first agreement for US$ 7.5 million over three years was signed, and then a second one for another three years. Memisa remained present as a partner in what was in practice an ITM-PNLTHA-INRB collaboration with a very developed control dimension despite being officially a research programme.

In the span of 12 years, support to HAT efforts in the DRC went from being control-focussed to being almost only constituted of research funding. Only some of the annual reports of the PNLTHA provide financial information for some of the sources of financing of the programme (they also list funders without any amount, suggesting the data is incomplete). Compiling information from the reports nevertheless confirms both the limited share of the Congolese State and the growing influence of research-oriented institutions (Fig. 4).

Among the practitioners interviewed in 2016, there was a clear sense that the balance between the resources allocated to control and those given to research was not optimal. A PNLTHA civil servant summed up the feeling of many:

> "Well, I think that if we can distinguish between research and control, it's a good thing […] It's when you get confused that it is not

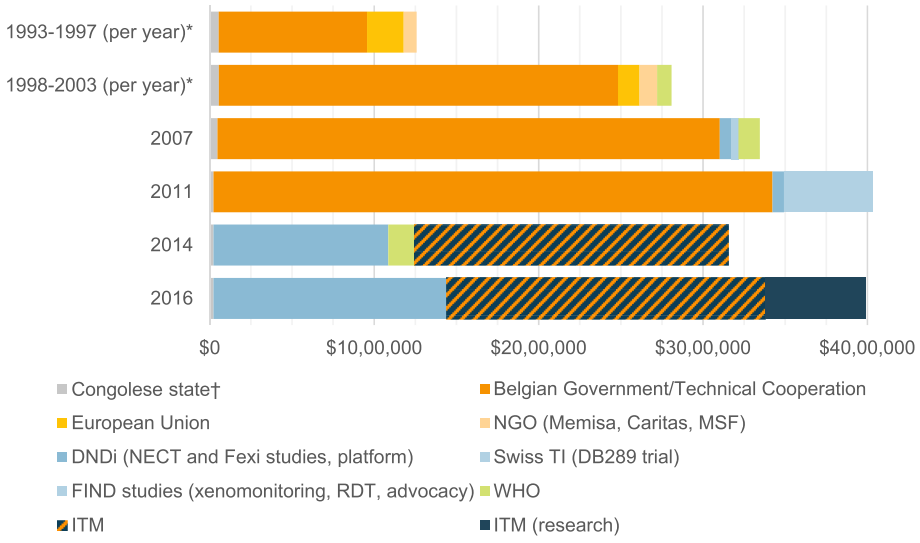

Fig. 4. (Partial) sources of PNLTHA funding*. Source: PLNTHA annual report and Lutumba et al. (2005) for 1933–1997 and 1998–2003. | * 1933–1997 and 1998–2003 are averages per year | † values for Congolese state inputs in 2014 and 2016 are estimates based on earlier years. |* It is hard to establish a comprehensive list of the contributions missing from the PNLTA report (the reports themselves do not claim to be comprehensive). In the early years, the contribution of Fometro (partly in goods) is not accounted for, while in later years, the substantial funding of the Bill and Melinda Gates does not appear in the reports we accessed and was not available from public sources.

pleasant because then you forget even the country's strategies in the fight." [HAT, 3]

A senior civil servant at PNLTHA further explained the tension, taking the case of the Bill and Melinda Gates Foundation:

> "We must bring them back [in line], we must help them because when we do research, the data, the information, it belongs to the country. Even if one wants to use it differently, one must have the country's permission. And that is why the programme must provide a framework." [HAT, 4]

The quote illustrates a feeling of undesirable distance between the national programme, described as the most legitimate actor in its country, and some international research projects. To be clear, the problem highlighted in the quote is not that something forbidden was committed—all projects had to be greenlighted by the PNLTHA and the Congolese ethics committee—rather, it is the feeling that he PNLTHA was not associated closely enough until late in project development. The fundamental issue is one of budget control: all interviewees point out that the key HAT control budgets of the early 2000s were established after substantial consultations with the PNLTHA, and some of these budgets were even co-designed between the partner and the programme. However, the PNLTHA, by its very remit and nature, had less of a natural and legitimate authority over international research budgets. The arrangement with the Belgian authorities to continue HAT control funding via the ITM, for instance, had significant drawbacks for the PNLTHA: the finances were held in Antwerp rather than Kinshasa, and the prime lens of the funding was research [INZI, 3]. In 1996 as in 2016, the BTC/PNLTHA had limited control over HAT budget: in 1996 because the resources were extremely limited, and in 2016 because the budgets were formally research budgets controlled by international lead investigators.

The shift in the funding landscape and Lutumba and Kande leaving their leadership position at the PNLTHA in 2011 and 2012 respectively meant that the PNLTHA took a new turn in the early 2010s. By then, Lutumba's research extended to Neglected Tropical Diseases beyond HAT, HIV/AIDS, and malaria and he was established as a leading medical academic figure in the country (he remained a scientific advisor to the PNLTHA until 2017). Kande also enlarged the remit of his professional activities as he was appointed to the Disease Control Directorate (*Direction de Lutte contre la Maladie*), the unit above the PNLTHA at the Ministry of Health. As the last sign that the times were changing, Fometro, once the over-dominant HAT actor in the DRC, was terminated when its last living trustee died. A legal battle over the ownership of the Fometro building, which also hosted the PNLTHA, ensued, with the PNLTHA eventually expelled from the building and many of its archives lost.

7. Concluding remarks

The landscape of HAT research and control in the DRC radically changed between 1996 and 2016, in part owing to the leadership and inventiveness of the national HAT programme. The DRC, a country often described as one of the most 'fragile', had and still has a well-regarded national HAT programme. The trio of doctors at its head grew and maintained it by making full use of a window of opportunity in external politics that emerged in the early 2000s: the renewed international interest in enhancing HAT control and making its treatment more humane. Our political economy analysis shows how the trio also carved out a supportive space in interest groups and bureaucracy politics (Sparkes et al., 2019). They developed solutions around the key issue of budget politics, thereby showing their agency to affect the institutions, the 'rules of the game', in which they operated. The PNLTHA directors went beyond the unfavourable balance of power (between them and well-endowed international research funders) and leveraged their context, including, for instance, access to patients who are key for clinical trials, to gather more support for control –this latter aspect would deserve more careful analysis, but it certainly complicates perspectives on the use and abuse of clinical trials in so-called low-income countries.

The PNLTHA's approach of funding and partnerships that we described was effective, but it was also always fragile, in the typical fashion that health programmes financially dependent on donors are (Witter, 2012). It is also not clear that the approach –which was and remains research funding-reliant– is sustainable as the number of new HAT cases keeps going down and the HAT-related technology improves. Many at the PNLTHA feared that the funding may dwindle: "a lot of donors are saying, why would we put millions of dollars for 2,000 cases?" [HAT, 17]. By 2016, the infection rate was 0.07% –of 1,428 people screened in areas of medium and high endemicity, one was HAT positive. This is 27 times lower than in 1998. However, HAT veterans were keen to remind us that near-elimination was already a reality in the 1960s and collapsed not because of the lack of technology but because of the lack of resources invested in control. This concern has been echoed by a few infectious disease experts already, notably in a 2010 paper that aptly asked in its title "when will they ever learn?" (Molyneux et al., 2010).

Our political economy analysis has also highlighted that the PNLTHA

was a quintessentially vertical programme (and still is at the time of writing). It was deliberately insulated from the rest of the Ministry of Health general activities, operating with its own structure; plans for further integration of HAT-specific activities into the general package of activities of health facilities did not come to fruition (at the time of the research; Mulenga et al., 2019). As we showed, such autonomy was at least partly by design; the heads of the PNLTHA 'protected' the programme, which also did not rely substantially on Ministry of Health resources and focussed on getting other financial resources. It may well have been 'life-saving' in a context fraught with political turbulence and interference, and the academic literature stresses the benefits of vertical approaches that allow "targeted disease control, clear goals and deadlines" (Klepac et al., 2013, p. 8). However, the same literature also points to clear limitations of vertical approaches of disease elimination. They become more visible later in the process of elimination, and especially in the 'last mile': when tracking the last cases, passive screening and treatment outside specialised clinics and mobile units are precious. Ultimately, it is not a matter of vertical versus horizontal but a question of integrating both in devising bespoke strategies (Ortu and Williams, 2017). Passive screening capacity and treatment, however, do not build overnight, and strengthening frontline health facilities in most of the DRC is far beyond the capacity of the PNLTHA. It requires political action at the higher level of the Ministry of Health, and therefore more, potentially dangerous exposure to the broader politics of health-care.

Our analysis of the DRC's national sleeping sickness programme between 1996 and 2016 is a current history, which will need to be reviewed, revised, and augmented with sources when they become available (from WHO, NGOs, and government, for instance). Nevertheless, we add a crucial element to the narrative of the 'road to HAT elimination': alongside drugs discovery and global health mobilisation, it is a story of national competence, inventiveness, and coordination. The sustainability of both the vertical approach and the funding model remains open questions, but our study provides insights for fruitful, even if always delicate, collaborations between unevenly-resourced international research and national disease control programmes in low-income countries.

Author statement

Conceptualization, **JBF**, **AM**, and Michelle Taylor; methodology, **AM** and **JBF**; formal analysis, **JBF**; investigation, **AM** & **JBF**; data curation, **JBF**; writing—original draft preparation, **JBF**; writing—review and editing, **JBF** and **AM**; funding acquisition, **James Smith**.

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Appendix A. Supplementary data

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