



**AN ANALYSIS OF RECENT INTERNATIONAL
COVERAGE OF THREE NEGLECTED DISEASES:
AFRICAN TRYPANOSOMIASIS,
LEISHMANIASIS AND CHAGAS DISEASE**

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DECLARATION:

Where other people's work has been used (either from a printed source, internet or any other source), this has been carefully acknowledged and referenced in accordance with departmental requirements.

This thesis, "*An Analysis Of Recent International Press Coverage Of Three Neglected Diseases: African Trypanosomiasis, Leishmaniasis And Chagas Disease*," is my own work.

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Journalists would cover these issues more if there was a greater attempt to engage journalists. [Neglected diseases advocates] need to make the time to talk to reporters.

– Journalist in London

There's a lot of misery on this planet and people are very selective about their misery. How, where and when determines if the story is newsworthy... A lot depends on what happens on your plate. There's a lot of material out there and we have to make decisions quickly. – Journalist from a wire agency

Neglected diseases... is that a show we can sell? It's very hard. We're not a charitable organisation, we have to work within our business model. We have to look at our audience and factor that in. – American producer from international broadcaster

It's a matter of the economics of journalism. Newspapers are retrenching [foreign staff]. They are looking to develop more local stories. There is generally less interest in global health issues. – American print journalist.

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ABBREVIATIONS

AIDS	Acquired Immune Deficiency Syndrome
AFP	Agence France Presse
BBC	British Broadcasting Corporation
CNN	Cable News Network
DNDi	Drugs for Neglected Diseases Initiative
FT	Financial Times newspaper
HAT	Human African Trypanosomiasis
HIV	Human Immunodeficiency Virus
IOWH	Institute of OneWorld Health
NDs	Neglected Diseases
PPPs	Public-Private Partnerships
WHO	World Health Organization

ABSTRACT

Title: An analysis of recent international press coverage of three neglected diseases: African trypanosomiasis, leishmaniasis and Chagas disease

BACKGROUND: This study aims to investigate, describe and analyse press coverage by the international media of three neglected tropical diseases (NDs) from 1 January 2003 – 1 June 2007. NDs have been “neglected” in almost every avenue of the health sphere. The extent of the pharmaceutical industry’s “neglect” of NDs has already been studied, but there are no studies about the extent and nature of the media’s lack of coverage on NDs. Understanding how NDs are covered in the media and in what context will be important in developing an advocacy strategy for NDs.

OBJECTIVE: To identify the extent, pattern and nature of international press coverage of three very neglected diseases, African trypanosomiasis, leishmaniasis and Chagas disease, to help support future media advocacy on NDs.

METHODS: A content analysis using quantitative and qualitative approaches was done. Online archives of 11 leading, international, English-language news media and databases in the British Library were searched and analysed. To be included as a sample, an article had to have at least two mentions of any of the three diseases or the term “neglected diseases”, or more than one paragraph which contained one mention of these search terms. Searches were also done for the terms “sleeping sickness”, “*kala azar*” and “black fever”. Articles with one mention of the term “neglected diseases” were excluded from the database but recorded separately to note how many times this term was used. Articles were identified and evaluated by media organisation, date, author (if available), type of report (such as an editorial), slant (positive, negative or neutral), themes and “frames”. Also, a questionnaire was drawn up and semi-structured interviews with nine journalists and four key informants were conducted to deepen this analysis.

RESULTS: The study confirmed media coverage of NDs was low. Only 110 articles over a period of 53 months from 11 media organisations met the inclusion criteria. There was a slight peak in coverage in mid-2005, but this did not appear related to an ongoing advocacy campaign at the time as the articles were on unrelated, disparate themes. Overall, the BBC had the highest coverage with 20 results, while its apparent competitor, CNN, had the least with one result. The *Financial Times* (FT) and *Agence France Presse* had the second and third-highest coverage respectively. Many media organisations used the term “neglected diseases” (the FT had 42 articles with one mention of the term), indicating this term has good media currency. “Sleeping sickness” was also more widely-used than trypanosomiasis. Leishmaniasis was the most well-covered disease and Chagas the least. Academic researchers were most commonly quoted as a main source, while WHO and the pharmaceutical industry were the least quoted. Journalists generally agreed that NDs had not been adequately covered, but added stories had to be newsworthy. A lack of real news development and the drive to cater to domestic audiences were the biggest obstacles for reporting on NDs. Coverage of global health issues was particularly poor in the American media, where health and foreign budgets have been cut. All journalists said health agencies were not communicating adequately about the burden of NDs. Some journalists were particularly critical of WHO and the Gates Foundation for the difficulty in reaching officials for comment.

RECOMMENDATIONS: Neglected diseases will require planned, sustained advocacy to bring them into the foreground. Public health agencies need to raise priority for advocacy and develop relationships with journalists. There is a need to broaden the context of stories to appeal to a wider audience or to localise stories for domestic audiences. Innovative ways to promote ND reporting may be necessary in today’s market-driven, cost-cutting environment of newsrooms.

<p>KEY WORDS : Neglected diseases, media coverage, international press, content analysis, African trypanosomiasis, leishmaniasis, Chagas, sleeping sickness, <i>kala azar</i>.</p>

1. INTRODUCTION

1.1 STATEMENT OF THE PROBLEM

Neglected diseases (NDs) are a group of mostly tropical diseases that have suffered neglect in many ways. They are of little interest to the pharmaceutical industry, thus safe, effective, affordable treatments are lacking; [1] they are bypassed by mainstream global health efforts, receiving little funding; they are neglected by governments, even in countries affected; and they are ignored by the media, rarely making headlines. Even public health authorities have underrated NDs – not subject to compulsory reporting in many countries[2], they are not perceived as health burdens or threats to society, unlike AIDS or tuberculosis. The neglect is not just about these diseases, but rooted in the communities affected: the world's poorest people.

In recent years, the tide has been changing. In 2003, the Drugs for Neglected Diseases Initiative (DNDi), was set up by Médecins Sans Frontières to help spur development of drugs. Through public-private partnerships (PPPs), mostly involving multinationals or small firms, new drug projects have flourished, with 63 ongoing by the end of 2004..[3] In 2005, Mary Moran noted in a key study, "The landscape of neglected disease drug development has changed dramatically during the past five years." [3] Initiatives to address NDs have also grown. But for the "very neglected" diseases of human African trypanosomiasis (HAT), leishmaniasis and Chagas disease, there is still much to do.

1.2 SIGNIFICANCE OF STUDY

The lack of pharmaceutical research in NDs and the drug gap from market failure has been studied. For example, a 2002 study found only 16 drugs were marketed for tropical diseases between 1975 and 1999.[4] However, no study has looked at NDs and the media. The media's "agenda setting" function is well recognised.[5] Any concerted effort to remove the "neglect" out of NDs must involve the media. This study, an analysis of media coverage of NDs, supported by interviews with journalists, aims to provide a context of the current media situation facing neglected diseases. In order to narrow down the search and to focus the study on a particular area, the three most neglected diseases were chosen for the study – HAT, leishmaniasis and Chagas disease. Results of this study will be important in developing future advocacy work.

2. BACKGROUND

2.1 THE BURDEN OF NDs

There are 14 NDs (an increase recently from 13), as defined by the World Health Organisation (WHO), which include seven helminth infections. (The phrase “neglected tropical diseases” is used by WHO, but “neglected diseases” is used here because it has broader public appeal and also not all NDs are confined to the tropics.[6]) The burden of NDs is substantial. Roughly one billion people – a sixth of the world’s people – suffer from one or more NDs.[7] If considered together, NDs represent the fourth most important group (by disease burden) of communicable diseases, after respiratory infections, HIV/ AIDS and diarrhoeal diseases.[8] They cause 35,000 deaths a day.[9]

Yet the real burden of NDs is not described by death rates. Many NDs do not directly lead to high mortality rates, but have enormous rates of morbidity and drastically reduce income of families.[6] These diseases often have the worst elements, being “disabling, disfiguring and stigmatizing”.[10] Some cause life-long disabilities. It is telling that ancient texts such as the Bible have described characteristic features of these diseases.[11] Leishmaniasis causes hideous lesions and can leave facial deformities. HAT, or sleeping sickness, causes untold suffering to caregivers too, who must watch helplessly as the loved one appears to lose their senses and requires constant care. By some estimates, NDs are only second to HIV/ AIDS in disease burden with a toll of 57 million DALYs annually.[6] It has been said that the real burden of NDs, and their impact on development, has been grossly underestimated.

NDs often affect the poorest of the poor in low-income countries. Moreover, parasitic diseases – whether transmitted by vectors or soil – generally tend to affect certain vulnerable groups such as school-age children, women of childbearing age and breadwinners in a household.[2] Often, NDs cluster together, in areas of unsafe water, substandard housing and poor sanitation and vector control, exacerbating the problem.[7] In parts of Asia and sub-Saharan Africa, much of the population is polyparasitized with one or more helminths or schistosomes, which affect children’s physical and intellectual development.[8] Some researchers now argue that coinfection with an ND could adversely affect the progression of disease of HIV/ AIDS, tuberculosis and malaria. Anaemia is one of the most important comorbid conditions.

Despite this toll, the control and treatment of NDs is often appalling. Tools that exist do not always get used or delivered to the poor. [6] Low-profile diseases, NDs are often left out when public health agendas are drawn up. Those affected usually have little political voice – thus Bernard Pécoul of DNDi has called them the “forgotten people”. NDs also draw less donor interest because “they do not travel easily” and pose little real threat to wealthier societies.[7] Drugs for NDs are badly lacking, in short supply or not easy-to-use. The problem is rooted in the inability of the poor to drive a market for new drugs. Of the 1556 new chemical entities brought to the market between 1975 and 2004, only 21 (1.3%) were for NDs, a 2006 study found.[12] The chance of a drug being brought to market for nervous system disorders or cancer was 13-fold greater than for a ND. A 2002 study found eight of eleven leading pharmaceutical companies spent nothing on the three most neglected diseases - HAT, leishmaniasis and Chagas disease – in the previous fiscal year.[4] These diseases especially lack safe, effective, affordable drugs. No effective drugs for chronic Chagas disease exist. HAT is still treated with drugs dating from colonial times, including the poison arsenic, which, tragically, kills at least 5% of patients.[13]

A surge of public-private partnerships (PPPs) have led to a flurry of new drug projects for NDs, one of which resulted in a new drug for leishmaniasis (paromomycin). There are also other tools for disease elimination, namely vector control – these three diseases are all spread by vectors. HAT was previously controlled in Central Africa, but has resurged since the 1960s because of conflict and poor health services.[14] Chagas has been eliminated in five south American nations but is still a problem in some countries.

2.2 INTO THE FOREGROUND

In recent years, considerable effort has been made towards improving the health of the world’s poor. The vast majority of new initiatives and increased funding have focussed on the “big three” killer diseases – HIV/AIDS, tuberculosis and malaria.[8] NDs have remained in the background, despite their substantial burden (although a lesser one than that of the “big three”) and their potential to be addressed at “realistic costs with effective interventions”. The cost difference is huge. While the treatment for HIV/ADS exceeds \$200 per year per person for the life of the person, seven major NDs could be treated in Africa at just US\$0.40 per person annually. [15] The returns of investments into controlling NDs are clear, with annual rates of return between 14 – 30%.[14] This

situation of the inordinate focus on three diseases has been severely detrimental to the social and economic wellbeing of the very poor in the poorer developing nations.[16]

Part of the problem, according to Professor David Molyneux of the Liverpool School of Tropical Medicine, is poor recognition of NDs. Speaking to the BBC, he said: “These diseases are off the radar screen. They are major public health problems but they do not have names that people identify with because they do not occur in the West.”[17] Thus, the key difference with the “big three” to NDs is their high media profile and their presence in developed nations. A strong, vocal activist group for HIV/AIDS has also been important. Thus, there is a clear need to increase advocacy and awareness of NDs, particularly as those most affected by NDs have little vocal advocacy, even within their own countries, to get diseases on public agendas. The media’s role in shaping public opinion and policy has been well-documented. Studies examining media coverage have shown that news reporting can be a “significant ‘background’ to policy change”.[18]

This study will help support future advocacy work of NDs, which will be essential if NDs are to move from the background into the foreground of global public health efforts. The author is not aware of any studies on NDs and the media. Understanding how the most neglected diseases are covered in the media and in what context (what, where, why, how) will be critical in developing effective media advocacy strategies. Attitudes of journalists would help identify the current news agenda and what is “newsworthy”. Ultimately, a higher media profile of NDs will be essential to help remove the “neglect” from these diseases.

3. OBJECTIVES

The general objective of this study is to identify the nature of press coverage on NDs, including strengths and weaknesses, to strategise improved media advocacy on NDs by public and private organisations and partnerships in the field. Specific objectives are:

- (i.) To investigate and describe the extent, pattern and nature of news coverage on three “very neglected” diseases (HAT, leishmaniasis and Chagas disease) in selected media over a four-year period (June 2003 - June 2007).
- (ii.) To identify possible factors influencing news coverage of NDs by interviewing journalists from selected media on their current perceptions of NDs and limitations in their reporting of NDs as well as other key informants, mainly communications officers from WHO and MSF.

4. METHODOLOGY

4.1 DESIGN

The study was a content analysis of the media employing a mixed methods approach. The quantitative component measured the number and nature of news articles in various major, international English-language media, well as any trends and patterns. Data was collected from online searches of electronic databases of news media as well as from resources at the British Library (Newspapers) in London, which has an extensive database of news clippings. The methodology employed for the content analysis was based on ample literature on this type of analysis. Through coded variables, the type of articles, the organisations cited and the slant of the articles (in the interest of ND advocate goals) were noted. Many articles quoted more than one person, but the main or primary quote which summarised the essence of the article was taken. It was usually not difficult to identify this. Where another quote was also significant, this was also noted. The amount of coverage in each media organisation and trends of coverage over time were also recorded.

A qualitative analysis was then done to determine the focus and perspectives of the articles by identifying themes and “frames”. The lead paragraphs and headlines were often key indicators to assess how journalists were presenting issues to readers. Additionally, the content analysis was supplemented by interviewing 10 journalists and four resource people on their perspectives of NDs, the current news agenda and what possible obstacles stood in the way of ND coverage.

The following hypotheses guided this study:

- **Hypothesis 1** – media coverage of NDs is poor but has been slowly rising since 2003;
- **Hypothesis 2** – media coverage rose after 2005, following DNDi’s campaign.

4.2 SAMPLE

The databases of 11 selected news media were searched: BBC online, CNN.com, the international news wire *Agence France Presse*, the American news magazine *Time*, the international news magazine *The Economist*, the international business paper *Financial Times*, two British newspapers – *The Guardian* and *Daily Telegraph* – and three American newspapers – *The New York Times*, *Washington Post* and *Los Angeles Times*.

These media were selected primarily for two reasons. First, because all of them are “international”, in that they have foreign wire services or print editions or broadcasts which reach developing countries. The *Financial Times*, for example, has an American and German edition. The *Guardian* has a weekly international paper while all the other newspapers also sell their stories to news media abroad. The LAT-WP news wire was described as the “world’s leading supplemental wire service” in an American Journalism Review survey. Secondly these are also key media domestically that could have a possible influence on international health policy through reaching donors and policymakers with significant financial and political weight.

It was felt that it was important to include at least one international wire service. With the decline of foreign correspondents in newspapers, due to shrinking news budgets, news media have tended to increasingly rely on wire services for foreign news. Thus, the world’s leading wire services – namely Reuters, *Agence France Presse* (AFP) and Associated Press – help set the foreign news agenda today. The wire service selected

was AFP, the world's oldest news agency, because it has the most far-reaching network of any wire service, with journalists in 165 countries. Reuters was also going to be included initially but due to time limitations, this was not possible.

Initially, the search was extended to France and Germany, to newspapers such as *Le Monde* and *Die Zeit*. However, there were limitations of time and resources, in addition to the difficulty of conducting a content analysis in a foreign language. Thus, during the period of this study, it was decided that the search remain limited to English-language media. This was unfortunate as *Le Monde* had a considerable number of articles on NDs – possibly larger than any of the media selected. A possible area for future study, thus, is a content analysis of the French media.

It was thought initially that searching on the British Library's "Newsbank" would be a useful database to search from, as it contains dozens of news organisations. However, as the database focuses primarily on the British media, it was felt there would be no additional value in searching this database. Instead, by carefully selecting which media to search on, a wider, more representative sample could be obtained.

Most of the news media selected were print media because of the difficulties involved in obtaining complete records of radio or TV coverage in various countries. As print media and television coverage is generally strongly correlated, this was not expected to significantly distort the findings of the study. Other media coverage analyses have also focussed only on newsprint media for the same reasons.

The period to be studied was chosen around a key campaign for NDs – the DNDi appeal in June 2005, stretching from about two years before and after this date: 1 January 2003 – 1 June 2007. This would allow for any trends from mid-2005 to be noted.

The search terms chosen included "neglected disease" and the names of the diseases – trypanosomiasis, leishmaniasis, Chagas disease – as well as other names these diseases are known by – "sleeping sickness", "*kala azar*" and "black fever" (a literal translation of "*kala azar*" in English. "Black fever" has been used by the US media – in fact, two articles in this search only used the term (and not leishmaniasis or *kala azar*).

4.3 INCLUSION CRITERIA

The inclusion criteria for articles were based on similar criteria used in other content analysis studies of media reports. To be included as a sample, the article must have some focus on these diseases, (rather than just mentioning them), which was defined as having at least two mentions of any of these diseases or the term “neglected diseases”, or having more than one paragraph about any of these diseases or NDs in general. In circumstances where there was only one mention of the term “neglected disease” but the article was primarily or entirely focussed on the subject, evident from the lead paragraph and headline, then it was included as a result. Articles focussing on other NDs, such as malaria or schistosomiasis, were not included. This helped greatly to narrow the search which allowed for the entire dataset to be used (eliminating random sampling). In general, it was not difficult to identify articles that met the criteria.

Additionally, a count was made of all articles that had one mention of the term “neglected diseases” in order to have an estimate of how many times this term appears in the media. These articles were not included in the content analysis, as they were focussed on other subjects.

Articles that cited the organisation “Drugs for Neglected Diseases Initiative” – which would automatically come up in the search because it included the term “neglected diseases” – were not included unless they had specific content about the three very neglected diseases being studied, or neglected diseases in general. Thus articles that referred to DNDi and malaria (such as recent articles on the new fixed-dose combination of artesunate amodiaquine, or ASAQ), were not included. This helped narrow the search to the subjects being studied.

References to the search terms *not* related to the diseases were also *not* included. For example, the term “sleeping sickness” was sometimes used colloquially by the media to disparage lazy footballers or politicians. References to the condition sleeping sickness “narcolepsy”, (which appeared in many stories on the American athlete Kelli White) were also excluded. References to “neglected diseases” which were on other unrelated diseases, such as rare “orphan” diseases in the United States, were also excluded. Travel articles were initially excluded but because there was sometimes a thin overlap of interest, they were later included.

4.4 CODING VARIABLES

In the past, there has been a variety of approaches used for analysis of text. In recent years though, coding and analysis systems to review media coverage have been developed quite extensively. Much work has been done with tobacco issues, with careful, systematic monitoring of media coverage in the United States and in Australia since the 1990s. [19] Tobacco advocates have developed the idea of “framing” news, that is, using a certain “frame” for a story to highlight specific aspects of an issue.

A quantitative analysis provided observable data on the extent of coverage. Articles were tabulated by disease and numbers, using Microsoft® Excel, to note which media organisations did stories and what diseases and issues were covered. A “general” category was set up for articles discussing more than one ND (but not on any disease in particular). Articles were identified by media organisation, author (if available), date and type of report (such as opinion piece or news article). Articles were categorised with a coding protocol adapted from coding systems used in other analyses.

A qualitative analysis helped analyse the orientation, focus and approach of articles. Frame analysis has been described as a “means of explaining the ways that dominant news discourses evolve and come to define... a problem”. [18] Framing can promote “a particular problem definition, causal interpretation, moral evaluation and/or treatment recommendation.” [20] Tobacco advocates have worked considerably on developing “frames”. A methodological framework for analysis, entitled “*Coding the News*”, was used to track press coverage of tobacco issues in many US communities. [21] This framework identified 13 overarching themes, a list of topics (such as addiction) and frames. Examples of frames are “tobacco as a legitimate business” and “youth portrayed as vulnerable”. Frames have helped advocates strengthen their campaigns.

Every article in this study was given a theme and a frame. However, common problems with doing this immediately arose, namely an overlap between frames or identifying a main frame when there were several. Themes were more immediately obvious, often elicited from the lead paragraph and headline, as these often summarised the direction and essence of the article, and focussed on what is most newsworthy. However, frames were more difficult to draw up. Perhaps this was because a wide number of diseases and issues were being looked at, rather than one particular issue (such as drunk driving). Difficulties in identifying frames have been noted in previous studies, which

is why some studies have only used frames for strongly opinionated articles. [21] Two frames that emerged here are “Big Pharma ignoring poor” or “hope for cure for the poor”. As some frames and themes converged, and because of the difficulties with frames, the themes and frames were combined in one category, which was again analysed, revised and narrowed down. It was useful, nevertheless, to initially have separate categories.

Other categories used in the analysis were the slant of reporting (if the article was favourable to NTD advocacy objectives). It would have been helpful also to note the depth of reporting, because there was a wide variety of depth in coverage, indicating the reporter’s understanding and awareness of the issue. However, this was difficult to analyse and code into a variable. It became very evident, though, which news media presented more profound analyses of the issues.

4.5 QUESTIONNAIRE AND INTERVIEWS

The second part of the study was to conduct semi-structured interviews with leading health journalists. This was to deepen and extend the analysis of media coverage and provide insights into the findings. A questionnaire was drawn up (see Appendix 1) and pilot-tested. Journalists were asked what factors influenced their reporting. Interviews were recorded, transcribed and analysed. All journalists that had more than three stories in the search results were contacted. However, many journalists did not respond, and of those who did, there was often difficulty reaching them. Nevertheless, interviews with 9 senior health editors, producers or journalists were conducted from key organisation including BBC, CNN, Reuters, AFP, AP and the Washington Post. Two journalists requested not to be quoted as they did not want to be seen representing their news organisation. Those interviewed included leading global health journalists such as Andrew Jack from the *Financial Times* (FT) and John Donnelly from the *Boston Globe*, as well as David Brown from the *Washington Post* and Maryn McKenna (formerly with the *Atlanta Journal Constitution*). In addition, four key resource people were also contacted, including two former WHO communications staff – Samantha Bolton, now a communication advisor for DNDi, and Roy Wadia, now director of communications at the British Columbia Center for Disease Control, also formerly of CNN, as well as a health journalism academic and former journalist, Dr Gary Schwitzer, from the University of Minnesota. These interviews proved very helpful.

5. FINDINGS

Hundreds of articles were scoured from 14 media organisation in this study.

Eventually, the number of organisations was narrowed to 11, as the French and German media were excluded, for reasons stated earlier. Most of the articles reviewed did not meet the inclusion criteria as search terms were only mentioned once. Typically, a search result of dozens of articles would yield only a fraction that met the inclusion criteria. Some articles were forms of a previous story (such as a web or print edition). Also, some articles came up in searches for different terms, but had to be counted only once. For example, an article discussing drug development of NDs might come up with the search term leishmaniasis, as well as “neglected diseases” or “sleeping sickness”. Such an article would be categorised once under the “general” category.

In summary, the main outcome of this search was not surprising – that NDs are indeed neglected by the media. Yet what was interesting was that there was a wide variety in the extent and number of articles between various media, and over the period studied, indicating the possibility for increased media coverage.

5.1 TOTAL ARTICLE COUNT

In total, the search on 11 media organisation over a period of more than four years (53 months), from Jan 1 2003 – Jun 1 2007, found only 110 articles that met the inclusion criteria, that is focussed to some extent on the three diseases being studied or “neglected diseases” in general. This works out to an average of 10 articles per media organisation over this period. By contrast, a search for AIDS would generally yield several times as many articles. For example, an unfiltered search for AIDS on the Agence France Presse database during the same period found more than 1,000 articles. A graph of this data provided immediate information for Hypothesis 1 and 2 (that media coverage has slowly risen since 2003, particularly after 2005). Media coverage did rise slightly to a peak in coverage in mid-2005 and a dip in the first quarter of 2006 (see Figure 1 and 2), but there was not a significant rise over the total period studied.

FIGURE 1 – Line graph of number of articles by year (per quarter) in period studied

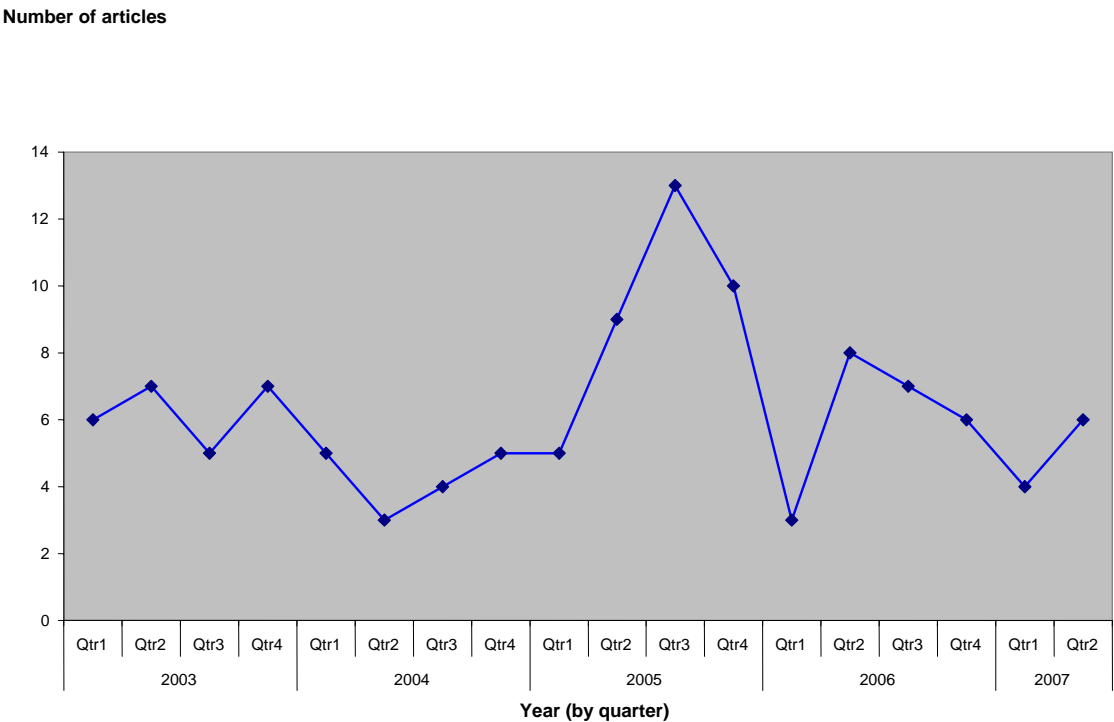
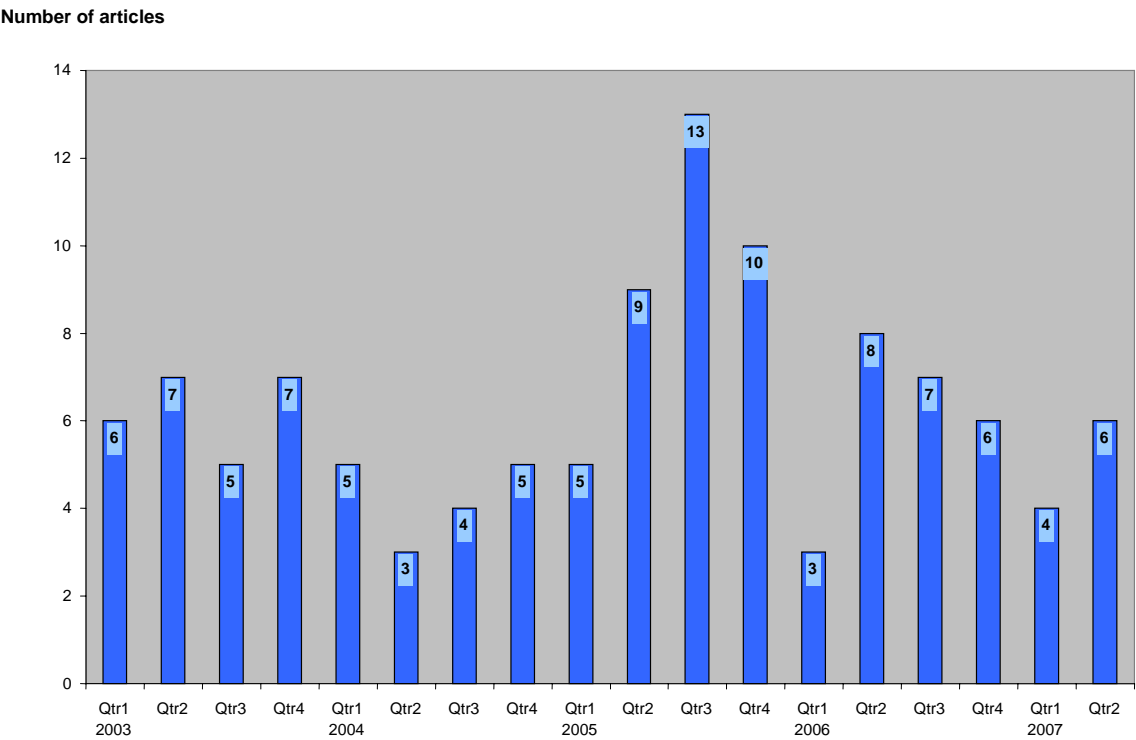


FIGURE 2 – Bar graph of number of articles by year (per quarter), with values



One might assume this peak was due to the DNDi campaign on NDs in mid-2005. Yet only one article was on the DNDi campaign. The rest were on disparate themes, from scientists cracking a genetic code to a rare outbreak of leishmaniasis in Ethiopia. There were a number of articles on sleeping sickness, which did not seem to be related to the campaign at all. Two were from the BBC, one relating the story of a woman who had battled the disease in Congo. There was also an article about increased funding for sleeping sickness from the Bill and Melinda Gates Foundation.

Other peaks and troughs in the curve were also not easily explained. Reporting on NDs tends to be sporadic and random. However, a few events prompted clusters of articles:

- A conference in Nairobi, Kenya, on NDs in May 2003 (three AFP stories);
- Scientists “cracking” the genetic code of the three diseases;
- A UK university receiving 8million pounds for tropical disease research;
- Development of paromomycin for leishmaniasis treatment by the Institute of OneWorld Health (IOWH).

In general, however, few events or developments generated interest from a wide range of the media. A breakdown of media coverage by disease can be seen in Figure 3. This shows that the “general” category garnered the most coverage while Chagas the least.

5.2 MEDIA ORGANISATIONS

All articles were tallied to media organisations. A note was also made of articles with one mention of the term “neglected disease” to get an idea of the media currency of this term (see Table 1). The news organisation with the most coverage was the BBC. There was generally a wide variety of articles and a relatively large number on sleeping sickness. A number of stories were not really seen elsewhere, including stories with a “human interest” that depicted the problem with the disease in the country affected. Such stories were often missing from the typically “hard news” coverage of other news media. One article interviewing Professor David Molyneux discussed how disproportionate attention to the “big three” diseases of AIDS, tuberculosis and malaria were overshadowing other NDs, which often had more cost-effective treatment and control programmes.

FIGURE 3 – Number of articles by each disease category by year (by quarter)

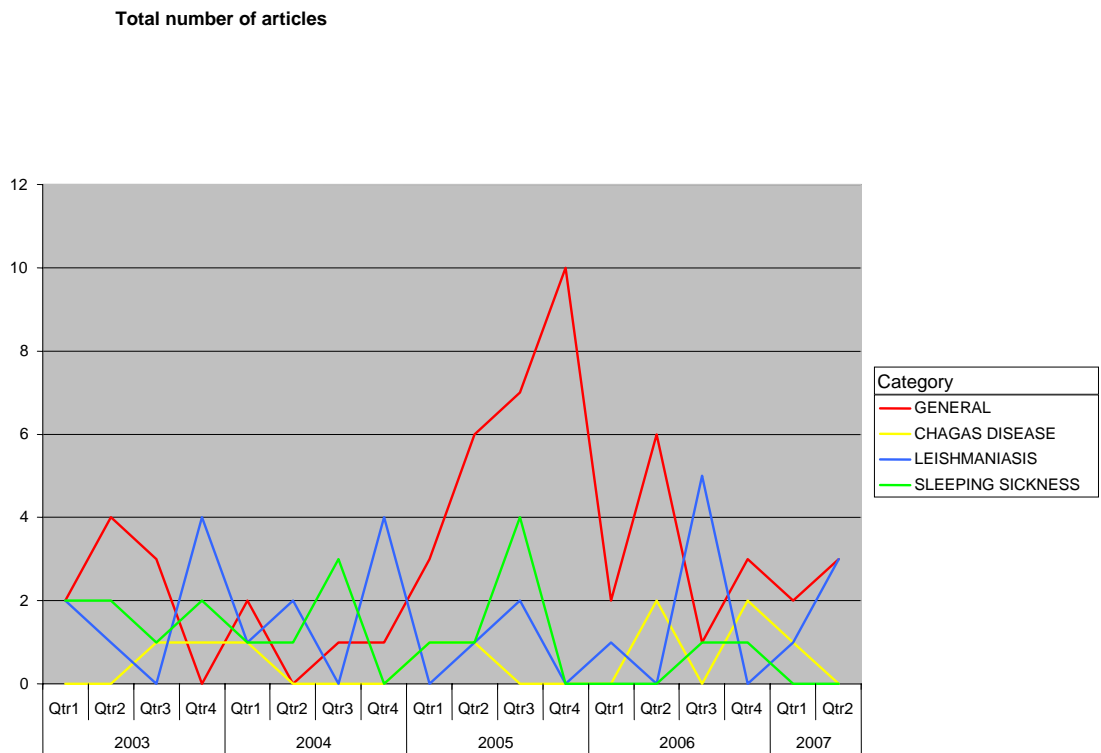


FIGURE 4 – Number of articles by media organisation over study period

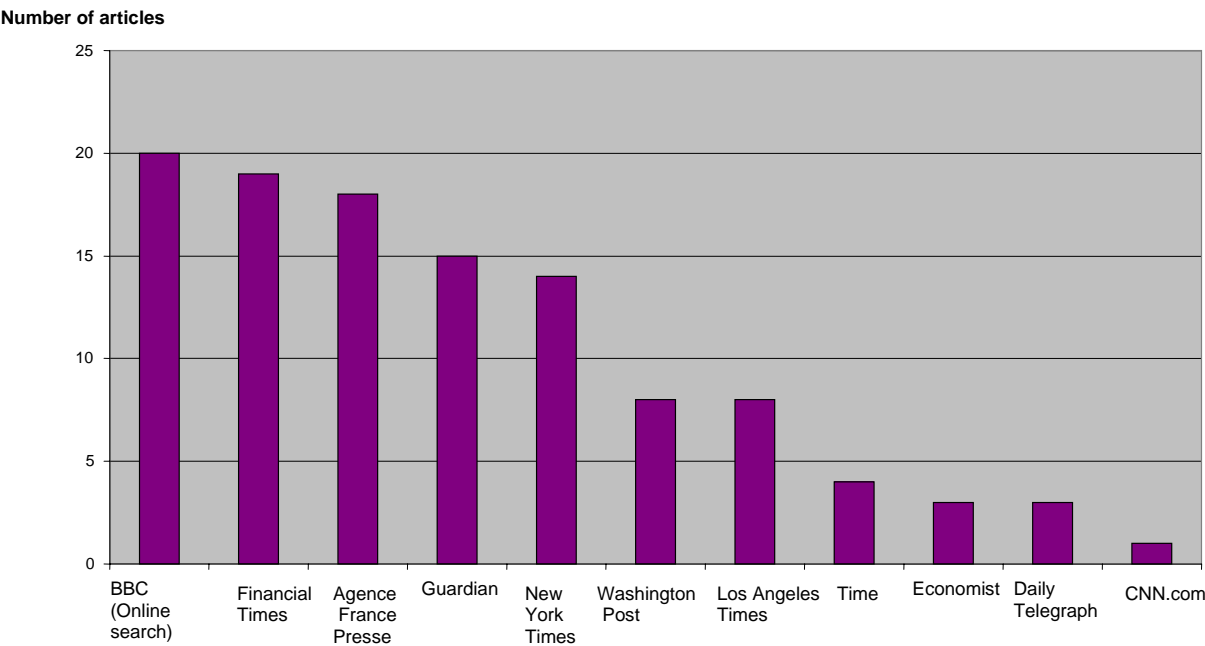


TABLE 1 – Articles found for each news organization

Media Organisation	Total # Articles	General	Leishmaniasis	Sleep. sickness	Chagas	# Articles 1 mention of “NDs”
BBC (online)	20	8	3	8	1	8
Financial Times	19	17	0	2	0	42
Agence France Presse	18	7	6	5	0	15
The Guardian	15	8	5	2	0	18
New York Times	14	4	6	1	3	11
Washington Post	8	5	1	0	2	5
Los Angeles Times	8	2	2	1	3	4
Time Magazine	4	2	1	0	1	8
The Economist	3	3	0	0	0	7
Daily Telegraph	3	0	2	1	0	0
CNN.com	1	0	1	0	0	0
Grand Total	113	56	27	20	10	118

However, although the BBC’s coverage was slightly more than the FT, they were less in-depth and involved than that of the FT, which had the 2nd highest coverage. They also tended to follow typical themes, for example, echoing activists calls for more funding or scientific developments. One television series aired on BBC World, “*Kill or Cure*”, featured half-hour episodes of a number of NDs, including all three relevant to this study. However this did not come up on BBC’s search engine because it was produced by a private organisation, Rockhopper TV, which received external funding for the series and sold the programme to the BBC. It was thus not strictly a journalistic mode of operation and was not part of this study.

The FT’s coverage was high both in quality and quantity, with 19 articles (17.3% of all articles) focussed on “neglected diseases” (defined as more than two mentions in the article). The articles were often in-depth and detailed, and adopting perspectives not readily taken up by other reporters, yet still retaining a “newsworthy” element. This

indicates the possibility of making news out of NDs, although it may take some creativity and the reporters' interest. One article took a critical look at public-private partnerships (PPPs); another looked at how DNDi worked. Also, it should be noted that the FT also had 42 other articles which mentioned the term "neglected disease", indicating the phrase has high currency in the newspaper and is discussed. Andrew Jack, the FT's pharmaceutical correspondent, had the largest number of bylines in this study. His reports on NDs have taken him to far corners of the world, including to South Asia to follow Bill and Melinda Gates and to California to investigate the work of Victoria Hale and IOWH. One story looking at DNDi quoted Pascal Millet.

The wire agency AFP had the third-highest coverage. This was not surprising. Wires produce a massive number of stories by day, many of which are much shorter than those in the American and British broadsheet newspapers. AFP also has a strong international base. Many articles were framed supportively towards the cause of NDs. There were also three articles focussing on sleeping sickness in Africa and another three on leishmaniasis. There were, however, no articles focussing on Chagas.

The news media with the least number of articles was CNN.com. Thus the difference between CNN and BBC, two television broadcast media purportedly trying to reach the same audience, was enormous. The only CNN story that came up in a search – and only on the international, not US, edition – was not produced by CNN, but Reuters. It focussed on an area of current American interest: Afghanistan. The story, "*Disfiguring skin disease plagues Afghanistan*", looked at the pervasive and damaging effect of leishmaniasis in the country. However, this story – dated 9 May 2007 on CNN – was taken off the site in June, probably because of copyright laws about archiving wire stories. It was retained in this study as it was available during the period of study.

The American news magazine, *Time*, also had a low number of articles (although it is a weekly) with just four stories, none of which were hard news stories – one was a letter, two were news briefs and the other a blurb about global health videos online. By contrast, *The Economist's* three articles were of far higher quality, with long, in-depth analyses and strong editorialising. One article in the weekly magazine concluded, albeit perhaps sardonically, "It is indeed an irony that... the wicked drug firms have discovered the value of not-for-profit business at precisely the point when governments are contemplating... incentives more attuned to... tooth-and-claw capitalism."

The UK's *Daily Telegraph* newspaper was also poor in its coverage, with just three stories. One story was about a British kidnap victim in Colombia who got infected with leishmaniasis, another by a student for a writing competition about a Sultan found to have sleeping sickness, "*The mystery of a very sleepy Sultan*", and the third about leishmaniasis in pets, due to new pet passports. The *Daily Telegraph* is the best-selling British broadsheet newspaper with a daily circulation of 900,000 at the end of 2006, according to the Audit Bureau of Circulations Limited. It is also a conservative newspaper – a 2004 MORI poll found 60% of readers vote for the Conservative Party.

On the other end of the political spectrum is the *Guardian*, which generally has a middle to left-wing stance on issues. It is generally considered more open to covering stories from the wide umbrella of activist or non-governmental perspective under which NDs might fall. The *Guardian* had the fourth-highest coverage of the 11 news media surveyed, with 15 articles. Many stories followed the typical media line of pursuing "local" angles, with interviews of British scientists or researchers working on NDs.

Following the UK's *Guardian* was the *New York Times*, with 14 articles. Three articles were about the Institute of OneWorld Health; two about the charitable efforts of local schoolchildren who were so moved by stories of sleeping sickness in class that they rallied to do charitable work. These stories were published under the local "Metro" section. There were also stories on "black fever" in Iraq among troops and the spread of Chagas through the US blood supply. The *Washington Post* and *Los Angeles Times* had eight articles each. There were three stories in the *Post* looking at the issue of NDs, including an editorial welcoming the joint efforts of DNDi and Sanofi-Aventis to produce a malaria drug. The *Times* had three articles on Chagas. This is not surprising given the higher threat to Los Angeles – as one story reported, Chagas shows up in 1 in 3,800 blood donors there, compared to just 1 in every 30,000 for HIV.[22]

It is interesting to note that the news organisations with the top and third coverage both receive public funding – that is, are not operating on an entirely commercial basis. Also, it would appear there is a difference between the British and American media, as well as the more liberal and conservative newspapers, in the coverage of NDs.

5.3 DISEASE CATEGORY

Although the term “neglected diseases” is relatively new and not specific, it appears to have good currency with the media. The term was used by most media, sometimes to refer to human African trypanosomiasis, leishmaniasis and Chagas. Indeed, of all the articles, 49.6% (56 of 113) fell under the “general” category. Only the BBC had as many articles on one disease (sleeping sickness) as in “general”. The “general” category included articles with the term “neglected diseases” and articles looking at more than one disease. This difference in coverage by disease categories can be seen in Figure 3.

Of the three diseases studied, leishmaniasis was the most covered. There appears to be a number of reasons for this – mainly because of the wide reach of those affected, which includes US troops in Iraq (the focus of a few stories) and recent drug developments (paromomycin by the US-based non-profit organisation IOWH, which was covered well by the American media). The idea of an individual striving to solve the contracted, thorny problem of developing drugs for neglected diseases was widely applauded by the media. Victoria Hale, the founder of IOWH, was the focus of a number of articles, some looking at the new possibilities offered by public-private partnerships. She also received an Innovation Award from the *Economist* and made it to the *Time 100* list.

Sleeping sickness was the next most covered disease, although primarily by the BBC, which had eight articles on the disease. Some stories were from the field itself, such as the article, “*Waking up to Congo’s sleeping sickness*”; others focussed on greater funding for local researchers to develop a cure. The BBC’s many “stringers” (freelance reporters) in Africa may have been contributed these stories from the field. Most of these stories had a strong human element, which, one BBC editor said was important to the BBC. One video clip looking at the poor treatments available for the disease was advertised with the emotive quote: “Doctors must decide whether the disease or its treatment poses the greater risk to patients”. This report, which interviewed MSF doctors, was fairly detailed, discussing for example, the issues around eflornithine.

Chagas was the least covered of all the diseases, with only eight articles meeting the search criteria. There were no articles in the British media, apart from one in the BBC, on how Scottish blood donors with a South American parent cannot give blood (so was thus a local story). Three articles appeared in the New York Times – two on the risks posed by the rising number of blood donors with Chagas in the United States and one

on an unusual mode of transmission (an outbreak in Brazil was apparently caused by infected sugar cane juice). Three articles appeared in the Los Angeles Times, two of which focussed on the parasite's threat to the American blood supply, and the other on a new drug for the disease. One of the articles raised the hot topic of migration within the context. The other article on Chagas was in Time, but was simply a short note on where to get information on the disease. There was no article on Chagas which actually focussed on the problem itself in South America in any media.

5.4 SOURCES CITED

One might assume that advocates of NDs, such as DNDi, are a common mouthpiece and source for stories on NDs. Interestingly, though, the most common group to be quoted (in a main or leading quote) were local university researchers, (see Figure 5), accounting for 32% (29 articles) of the 92 articles with quotes (excluded here were, for example, editorials). Academics represent a local source, which the media often prefers. Some stories discussed academic research or new funds (such as Bill and Melinda Gates Foundation grant for Scottish scientists). But university researchers were also quoted in other stories. Journalists may turn to them because of easy access and apparent independence. Combined with the closely-related "medical researchers" group, researchers were clearly the main mouthpiece, accounting for 41% of all main quotes.

WHO was only quoted as a main source in just 4% of all stories, (mainly for stories referring to WHO activities), indicating poor visibility in the media. The Bill and Melinda Gates Foundation was quoted in just two stories (one being a feature on the couple in the *FT*). MSF and DNDi made up 18% of main quotes (17 stories). They were also quoted as a secondary source in a further 7 stories. Six stories on MSF were from the field (such as on a leishmaniasis outbreak) and three stories were on DNDi's formation. Very few stories were recent – only three were from 2006 and 2007 – suggesting coverage has dropped. There were also several stories quoting the IOWH and Victoria Hale positively. Few stories cited the pharmaceutical industry first and no articles quoted politicians first. The "other" category included the American Red Cross, the US Army and the World Bank. Also included were three entries for a Kenyan Research Institute (which was placed in this category to distinguish them from local researchers).

FIGURE 5 –Main source quoted in articles

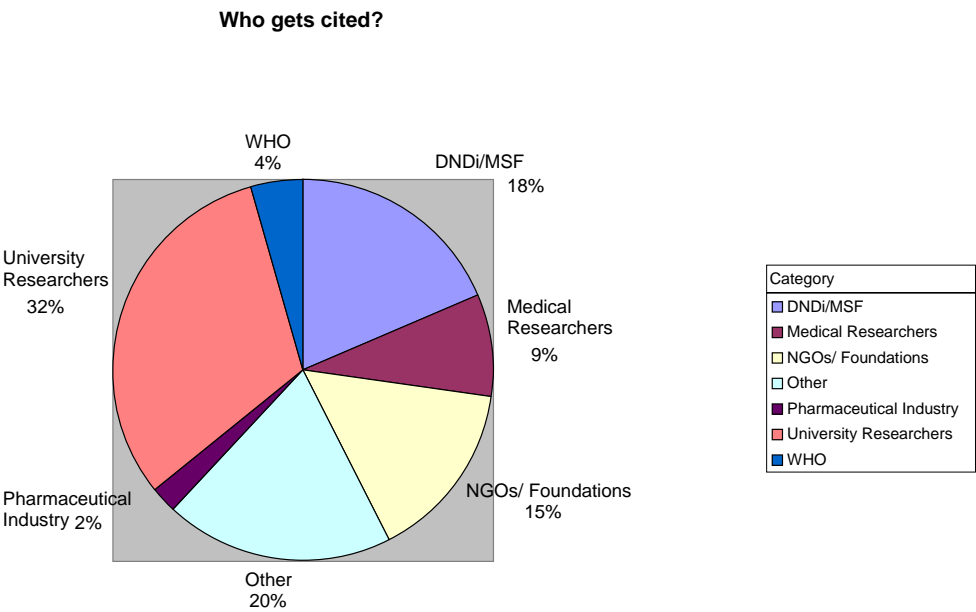
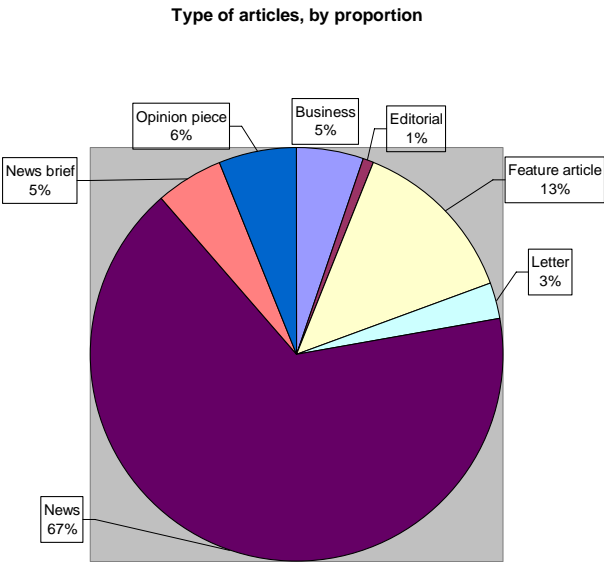


FIGURE 6 – Distribution of articles by type of article



5.5 ARTICLE TYPE

“Hard news” stories made up 69% (78 of 113) of all articles. This was not surprising, given that this is the mainstay of news organisations. There were additionally 17 features – although some “news” stories bordered as features. There were a small number of opinion pieces, including one by MSF staff in the FT and another by Nobel winner Sir John Sulston. Victoria Hale, of the IOWH, wrote an opinion piece in the New York Times. However, there was only one editorial (in the *Washington Post* on drug development, quoting Bernard Pécoul) and just three letters (including one from Jimmy Carter and one from an ND advocate). A third letter argued against NDs, arguing in favour of more “significant killers” (see 5.6). The small number of letters would indicate that neglected diseases do not evoke strong emotive responses among readers.

5.6 SLANT

The reporting was largely sympathetic towards NDs. Some articles even talked fairly negatively about “Big Pharma”. However, articles on Chagas largely fell into the “neutral” category, focussing on the threat to Americans from infected people of South American origin donating blood in the United States. Only one letter was considered “negative”. This was a letter printed in the FT (see section 5.5) critical of the focus on NDs. It argued that focus should be prioritised first to “significant diseases” that affect a wide body of the world’s population, such as diabetes and heart disease.

5.7 THEMES/ FRAMES

As described earlier, drawing up themes and frames were difficult, so the two groups were combined and further narrowed down. Some of the theme/frames were:

- Big pharma (6) – the industry under pressure, drug donation or on the defensive;
- Blood safety (5) – the threat from the Chagas parasite to the bloody donation system (nearly all these articles are from the US);
- Scientific progress through genes (6);
- The struggle to get drugs for NDs (9) (which includes stories on funding);
- The “horror” of the disease, describing the epidemic, victims, drugs and situation, sometimes with a personal account (14);
- Public-private partnerships action on NDs (15);
- The need to focus more on NDs (such as call for more research) (10).

5.8 QUESTIONNAIRE AND INTERVIEWS

The interviews with journalists were very revealing. NDs were clearly not a widely-covered topic. Journalists who did cover them were often personally motivated. Jack, (FT), the writer of the largest number of stories in this study, said that his reporting was “100%” driven by his interest. Reporters generally agreed that NDs were an important story that had not been adequately covered, but with the caveat that there were many other issues to cover and stories had to be newsworthy. Some comments were:

“The toll of human suffering [of NDs] is clearly high enough for the world to take a bigger interest.”

“There’s always a demand to do more, but you can’t fit in everything.”

“Stories about deaths from some unknown disease in remote [areas] have a tougher time reaching the international news agenda.”

“We’re not a charitable organisation. We have to work within our business model. We have to look at our audience and factor that in.”

“If there hasn’t been any new development, it’s not news.”

Much media coverage was focused on “breaking” news, (such as bird flu or the traveller with drug-resistant tuberculosis), or “big diseases and big events” which could easily create news, such as outbreaks and conferences. American journalists said domestic news dominated coverage. AIDS was a popular topic because it sells stories and has the funding and attention of policymakers. One wire agency editor said AIDS stories were actively planned ahead, yet stories on other diseases were “reactive”, such as on an appeal or a study. BBC Online’s Health Editor Richard Warry said:

“We write about AIDS about once a week. It gets well-hit... The media always has half an eye on its audience. We have a commercial imperative to focus on diseases that people are interested in. Breast cancer gets more stories because of the campaigns. We get complaints we don’t cover other cancers [well]. Our agenda tends to be skewed towards people campaigning... [they] are very vocal.”

The difficulties in covering NDs were manifold. The biggest barrier, many journalists said, was the lack of any real news development. Poor people dying from an illness is not news, as one producer from an international broadcaster said, and without some development or change in status quo, it will not be reported on. On top of this, there are many other stories to cover. One wire agency editor had, at the time of the interview, nine stories calling for his attention. Health communicator Roy Wadia, noted:

"There is great competition for air time and page space. It's a very crowded field for stories. It's not that journalists don't want to cover stories, but either they don't have the time or are not given the permission."

Another key factor was the poor domestic appeal in developed countries for diseases seemingly far-removed from audiences, particularly in the United States. As McKenna, former Atlanta Journal Constitution health reporter and author of a book on epidemiologists in the US Centers for Disease Control and Prevention, said:

"[NDs] are a very undercovered topic in the US. The American public isn't very curious about things outside our borders. Many journalists see it as 'way over there', a developing country problem... The media is unwilling to do something that is not going to be immediately recognizable to the population. It would be risky for commercial reasons. Everybody is checking hit rates on their website. "

Associate Professor Gary Schwitzer, director of University of Minnesota's Health Journalism Graduate Program, said American media organisations were cutting down on health correspondents and relying on wire services. Medical and science beat positions were being lost every month. International health news, he added, were virtually ignored. Thus topics like NDs, were going to fall "even further in editorial priorities". Foreign news coverage has also shrunk as more news media cut down on foreign correspondents. John Donnelly, a Boston Globe staffer who has reported extensively on global health, said a few years ago, he persuaded the paper to have an Africa bureau. But after three years, in 2006, the Globe closed all their bureaus and, like many American newspapers, now gets foreign news from wire services. He said:

"It's a matter of the economics of journalism. Newspapers are retrenching [foreign staff]. They are looking to develop more local stories. There is generally less interest in global health issues. To cover a disease half a world away, means you have to do it with [local] researchers. The bar is higher now."

On what could be done to improve media coverage of neglected diseases, journalists said stories needed to be made broader to have wider appeal. Stories that touched on the developed world, especially those that affected core readership, were "easier to sell" to editors. One example cited were the alternative models of drug development offered by PPPs. New developments in medicine were also easier to sell as stories. Personal testimony, that is the "human element", was also cited as advantageous by some

journalists. Wadia, a former CNN journalist, said that a story had to sell to both CNN's international *and* domestic audience to be accepted by editors. He said:

"You have to make a strong case of why this is important to your audience to convince your editors. News editorial choices are so arbitrary, even at places like CNN. It all depends on what a handful of people think. There are so many gatekeepers."

The *Washington Post*'s David Brown said it was important to educate editors and foreign correspondents, many of whom are focussed on politics and economics and know little about science and health, and fail to see where "rich sources of news" are.

Although the human angle helps to sell news, there is a huge resource constraint to do this for NDs, as journalists have to travel abroad to cover the story from the field. One journalist suggested NGOs could organise trips to the field for journalists to see these diseases first-hand. Samantha Bolton, communications advisor for DNDi, said:

"We have to take it down from experts and make it about real people. We have to show how disgusting these diseases are, to play up the 'yuck' factor. Otherwise, you won't grab the public imagination."

There were conflicting views about whether stories would have added appeal with the involvement of celebrities. Warry (BBC) said stories involving celebrities were thrown out. Yet without doubt celebrities have helped draw attention to global health in the American media. A recent cover of *Vanity Fair* magazine ran a special issue on Africa, with the pop star Bono as guest editor. The actor Brad Pitt was interviewed and even Madonna penned a piece. Journalists agreed that Bill Gates did add to "the newsworthy factor", raising the profile of NDs by increased investment. As Richard Ingham, Co-ordinator for Science, Environment and Medicine, *Agence France Presse* said:

"Gates getting his checkbook out changes the equation of how the story gets covered. There's a lot of misery in this planet and people are very selective about the misery... The perception in the public is that Africa is a basket case. Gates gives it a more uplifting angle. If you can shed light beyond the simple assertion that it's awful, then it's a good formula."

Asked if ND advocates and experts were communicating enough about the burden of NDs, nearly all journalists said more could be done. As Maria Cheng, from AP, said:

"It's a resounding 'no' and it's unfortunate. Journalists would cover these issues more if there was a greater attempt to engage journalists. The job of communications staff is to find what's newsworthy and make these stories available. To see a story materialise, there is a lot of

homework to be done. It's asking a lot for journalists to do this. The time taken to find a decent story on Chagas may not be worth the investment."

One journalist said that if advocates were doing a good job, there would be more coverage. Another criticised the "sanctimonious tone" of NGOs who felt that they media owed them due coverage, saying that they needed to engage actively with the media as the process was not passive.

NGOs were cited by a few journalists as good sources, particularly because "they are in the field and they see things". Donnelly (Boston Globe) cited MSF in particular:

"They have a very appealing way of pitching a story. They've been using [the term] 'neglected diseases' for years. The very term is a hook."

Of DNDi, which was not as well known generally, Ingham (AFP) said:

"They got off the ground well, although their record of alerting us has been a bit spotty. They could be a bit smarter about the way they illustrate [the problem]. Instead of just coming out with raw figures and appeals for money, if you really want to tap into [people's] concern, you have to exploit people's emotion and explain that this is an awful thing that's happening. They have to learn from other campaigns."

Journalists were critical about the communications work of WHO and the Gates Foundation – the key organisations in global health – and the difficulty in reaching officials for comment. WHO press releases were criticised for lacking news, being dull and "done to please donors". It was noted that a press release issued after a WHO meeting on NDs in April 2007 in Geneva did not generate any stories within this study. Some of the comments journalists made were:

"These two organisations... have the most conservative and slow media operations. It's impossible to talk to anyone at Gates [Foundation]. You have to email them. WHO is very conservative about what they put out. It's hard to get to talk to them."

"WHO works around the distribution of reports. There is no cultivation of journalists."

"Gates has the ability to make a lot of headlines if he wanted to, but he doesn't utilise his voice."

"Often, WHO press releases don't have any news but are done to please donors."

"WHO's pitfall is that they haven't taken communications seriously... One shouldn't blame the media entirely, if [such organizations] are failing to communicate."

6. DISCUSSION

This study confirms that neglected diseases are neglected by the media. The level of coverage by some media, such as CNN, is almost zero. Also, aside from a spurt of articles in the middle of the period studied, which was not readily explained by any event, no strong trends appeared. There was a slight but not significant increase in coverage from 2005. Otherwise, media interest was generally inconsistent and patchy, suggesting a need for a concerted drive to sustain media interest in NDs.

A search on Google News' Archives revealed an increase in coverage since 2005, as can be seen in Figure 7. However, this search in global media, (including for example, Angola Press) was unfiltered, and may have included multiple versions of the same story, such as wire stories being used in several publications. The increase could also be linked to technical features of the search engine or a greater, recent online presence of some publications. Nevertheless, the sharp rise after 2005 is worth noting. Bolton (DNDi communications advisor) also felt coverage was "definitely improving", largely due to PPPs, and NDs were generally higher on the agenda now.

This study shows the wide disparity between various media in coverage, which may indicate a possibility for increased coverage. Neglected diseases can be made into a good story, and also a good business story, as the FT shows. It can also be an emotive, human story, as some BBC reports show. Reaching the various media will take a variety of approaches. The use of celebrities was flatly rejected by some editors, while others were more open to the idea. The same formula is unlikely to appeal to all media across board. Different "angles" of a story are needed for different media.

Terminology is important. The term "SARS" was coined by a WHO press officer – it is short and simple like "AIDS". Human African trypanosomiasis appears to be too much of a mouthful for journalists and the public. Trypanosomiasis was rarely used alone by the media, which instead prefer "sleeping sickness" – it offers an immediate, visual description of the disease. The sharp difference in usage of these words can be seen from a search in Google News' Archives in Figure 8. This shows "leishmaniasis" is a more media-friendly term than "*kala azar*", which may be too foreign for the media and also relates to visceral leishmaniasis. However, in the study results, "*kala azar*" was often used. Some American media also used the term "black fever".

FIGURE 7 - Number of articles in Google News Archives (2003-2006)

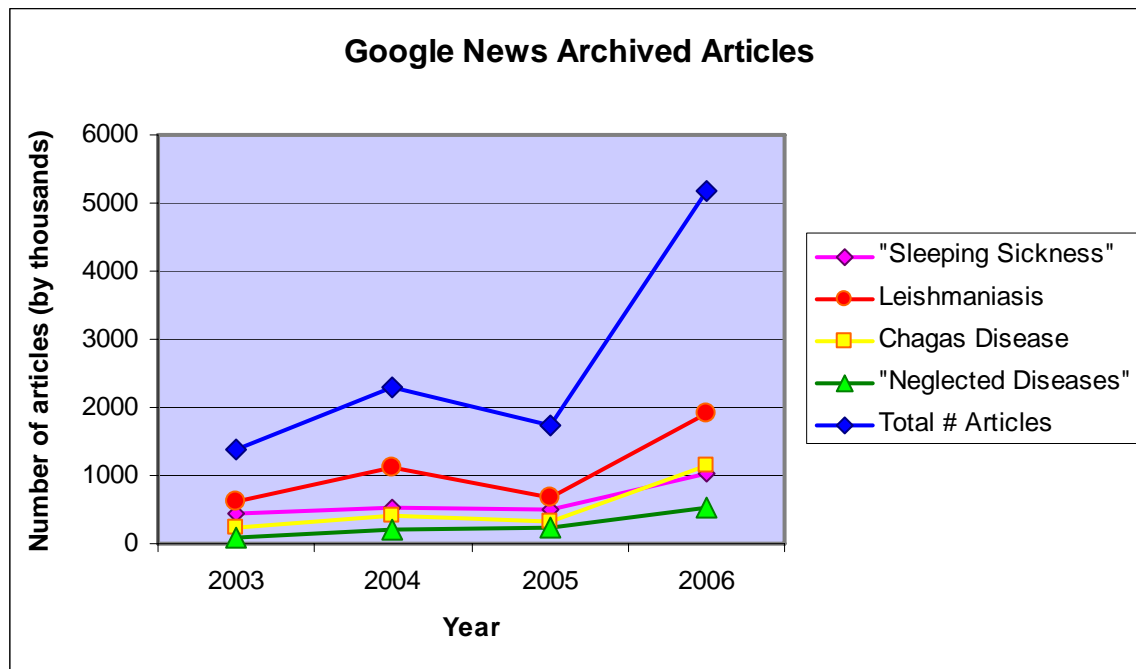
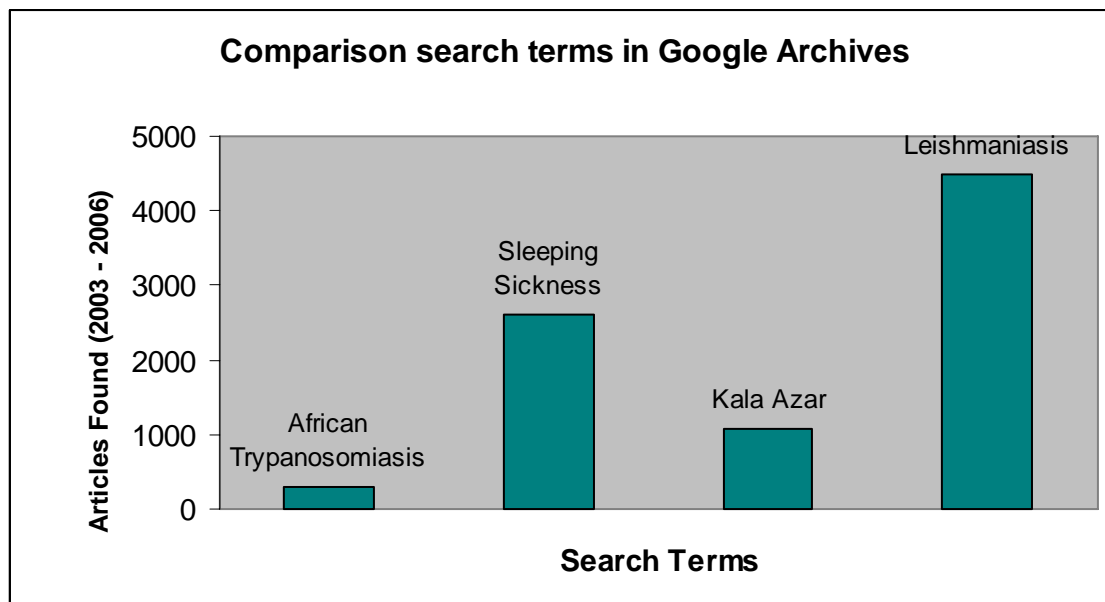


FIGURE 8 - Comparison of output from different search terms (in Google News Archives from 2003-2006)



The term “neglected diseases” evidently works; it has been picked up and used by many media, including leading American media and the FT (which had 42 articles with one mention of the term in the study period). It is easier to discuss these issues under an umbrella term than in specific diseases, which in any case, are not known to the public. Also, the term “neglected diseases” carries an emotive ring that conveys the inattention and gravity of the situation. Non-technical, it is a more “digestible” term for public consumption. As Donnelly (Boston Globe) said, the term has a “hook” which “gets attention”. In some literature, and in WHO, the term “neglected tropical diseases” is used, but this is more unwieldy and has no media currency. As “neglected diseases” has been shown to work as a term, it seems logical to continue to use this term.

Yet although appropriate terms and careful presentation of facts is important, that can only translate into stories if there is a newsworthy element. This perhaps is the greatest problem facing NDs – in such a neglected field, there are few developments that make good news stories, and even fewer that appeal to a developed nation’s audience. Of the stories in this study, many were about scientific developments, progress in research or increased funding for local academics for research. One article looked at the genetic overlap between the three diseases and the possibilities for treatment. Another article looked at how trypanosomes genes were related to plants and the potential that offered. Ways to make drugs more affordable or accessible was also a popular theme. Few events or developments generated interest across the board among the media however. Generally, stories about medical breakthroughs were popular news stories, as they fit the criteria for news. Indeed, they may become news *too* easily. As one study noted [23]:

“Newspapers reporting of health issues has been criticised for attributing too much certainty to research findings, for premature representation of findings as breakthroughs for being alarmist, incomplete or inaccurate... journalists seek health stories that will seize readers’ attention and... present... issues using straightforward, stereotyped themes.”

There is a traditional view that bad news sells. This is certainly true, but good news on NDs seems to make an attractive story, as was the case for Victoria Hale and IOWH. As one journalist said, good news helps uplift a very bad story. Utter hopelessness appear to be less newsworthy as misery with some hope! The Bill and Melinda Gates Foundation and other similar initiatives have helped to raise the profile of NDs in this

way. Stories with a broader context, particularly ones involving the developed world and the local audience, have a wider appeal and are easier to push in newsrooms. It is difficult to push stories that focus specifically on one disease in a remote country.

It is an old rule in journalism to seek a local angle for a story, but some news media appear to be getting increasingly parochial. A study on the type of research that made news in two British news media over a two-year period found no coverage on any research relevant to developing countries.[23] The tendency to localise means stories get written first about sick pets with leishmaniasis than human beings dying with the disease around the planet – as was seen in the UK's *Daily Telegraph*. The newspaper had no hard news story focussing on any ND, although one was published just outside the period being studied, on 19 June 2007, on a gene discovery of strains of leishmania parasites. The story was taken from a Wellcome Trust Sanger Institute press release.

The British newspaper at the other end of the political spectrum, *The Guardian*, was at the other extreme of coverage. A similar pattern was seen between the leading left and right-wing French newspapers – *Le Figaro* and *Le Monde*. Perhaps the news values of conservative news media rate issues such as access to drugs poorly. However, scientific developments and progress in drug development could still be newsworthy items.

However, the drive to appeal to domestic audiences is even more intense in the US media. In response to declining circulation and advertising revenues, media companies have slashed budgets for foreign news coverage (some newspapers have closed all foreign bureaus).[24] Despite the 2001 terror attacks, foreign news is losing ground. Market forces count for more than international affairs. Coverage of foreign news on front pages dropped from 27% in 1987 to 14% in 2004, a month-long study of front pages from 16 newspapers by the Project for Excellence in Journalism found.[24] Media bosses do not believe international news sells, said Schwitzer (University of Minnesota).

“There are so many misplaced priorities... There is so much attention given to new and unproven products. We don't tend to give health policy news the kind of attention they deserve, so we are a long way from giving international disease issues coverage.”

Yet one study found that polls showed an increased appetite for foreign news and, additionally, the circulation of a news magazine specialising in foreign news, the *Economist*, jumped by 15% in 2005, despite its high newsstand price.[24]

Commercial interests are driving news in American media organisations. This context may help explain why American media in this study had slightly lower coverage. The news media with the first and third highest coverage – the (British) BBC and (French) AFP – both receive some public funding, so do not operate on an entirely commercial basis. It may be that in a newsroom running on a commercial basis, it is harder to sell stories about unknown diseases in far-away places that have little domestic appeal.

Despite the increasingly narrow lens of the media, global stories can be localised through using local experts or finding connections that somehow bring a story home. Having a network of voices in various fields, such as academics, could help. The need to localise stories prompted the dean of Louisiana State University's mass communications program, John Maxwell Hamilton, to write a book: *Main Street America and the Third World*.^[24] The book details specific ways to localize stories, functioning as a "tip sheet" to make foreign affairs relevant to local audiences. There are some obvious possibilities for NDs. Chagas is now a problem for the American blood supply while some American soldiers have got infected with leishmaniasis. From this launch pad, stories could be broadened to encompass a more global picture, which is a picture ultimately affecting us all in an increasingly small, globalised planet. As McKenna said:

"Chagas is an excellent example of how necessary it is for American journalists to pay attention to diseases that we think would never affect us. Look how easy they cross our borders."

Amidst this challenging context, journalists have to face the pressure of putting together a story on relatively unknown diseases with limited sources of information. At present, what has driven the most committed reporters is personal interest. It is unfortunate that journalists have had difficulty reaching officials from WHO and the Bill and Melinda Gates Foundation, two key organisations. Timeliness is critical. As one journalist said of WHO: "By the time you get an answer to your question, your deadline has come and gone." Under the pressure of deadlines, a reporter may move to another expert or story. Providing ready access to information and experts when needed is critical to help improve coverage. Also, forming coalitions or networks – such as between PPPs and NGOs working on NDs – might help strengthen a voice in the media. Contact details of ND experts could be made available with key health organisations. Additionally, there is a need to cultivate relationships with interested journalists.

Just as it is necessary for organisations working on NDs to woo donors for funding, ND advocates have to attract and engage the media. That involves speaking the same language as journalists – in clear, intelligible language without medical terms and jargon. Bringing in a human interest angle and creating a visual picture of a disease can move a story. What is acutely missing in media coverage are vivid and powerful stories from the field, (very few stories quoted patients) and ND advocates should find opportunities to share such stories when available. Donnelly said “most health professionals are completely in the dark [about communications] but there are some stars”. Bolton has been battling this area, arguing to move moving away from experts in their “ivory tower” to “real people”. She suggests that PPPs work on a joint strategy “and not be afraid to sex it up.” She said:

“We have to gross it up, talk about tying patients to trees when they go mad. We need a face to these diseases. What’s the angle that’s going to make people really care?”

Yet all this is a low priority for experts on NDs: because funds are so limited, what comes available are usually “focussed on other things than communication” she said.

However, the battle to bring NDs out of the shadows does not rest just between the experts and the media but also the public. The disinterest of the media partly reflects the indifference of the public. The lack of letters (just three) shows this is not an issue that fires up people. Yet why does AIDS in Africa? The dreadful misery that these “very neglected” diseases cause, from unsightly wounds to disturbed behaviour, remains as hidden to the public as these diseases. If the public were made more aware of such tragedy, they might be more motivated to raise these issues in the media. A story in the New York Times demonstrates this.[25] When some schoolchildren in New York were shown a video in class on the horrors of sleeping sickness and the lack of decent drugs, they were so appalled about this “unthinkable” situation that they formed “Kids for World Health” (<http://www.kfwh.org/>), an NGO which has since expanded to France, India and Nigeria, raising awareness and funds and calling for action on sleeping sickness. Their actions also led to two stories in that came up in searches of New York Times in this study. Thus raising awareness does not have to follow traditional routes in the media, but can take many forms. At the same time, the tried-and-tested route of writing letters should not be overlooked as a way to raise awareness. Feedback, both positive and negative, keeps editors aware of what readers are thinking.

Clearly, there is a need for ND advocates to engage more actively with the media. But in the market-driven setting of today's media, more innovative strategies than advocacy alone may be needed. The same commercial context that constrains drug development of NDs also curbs reporting of foreign affairs and global health, notably in the American media. Just as public-private partnerships have transformed the landscape of ND drug development, some form of public-private funding may be needed to bring insightful, in-depth reporting on NDs from the field to readers in developed nations.

This idea is not entirely new. Many fellowships, grants and awards are available to American journalists to help promote reporting in a certain field. The Pulitzer Center on Crisis Reporting funds reporting projects from under-covered areas of the world and travel grants.[26] Freelance journalists submit proposals to the Center, which also helps place stories in leading American media. Director John Sawyer was quoted as saying: "I just think it's heading toward a direction where you need nonprofits." [24] Supporting HIV/ AIDS reporting is the Kasier Family Foundation, which provides online resources, trainings and health fellowships to journalists. Its latest initiative is "The International Health Journalism Fellowship Project" to support global health reporting.[27] Harvard University also recently began Nieman Fellowships in global health reporting. Both these fellowships are funded by the Bill and Melinda Gates Foundation. Other alternatives include having NGOs taking journalists to see diseases in the field, (although this raises the thorny issue of independent reporting). Without such initiatives, global health reporting remains subject to the vagaries of market forces, which may leave the voices of millions in the developing world to go unheard.

6.1 STUDY LIMITATIONS

This study looked at selected, English-language international media. For the purposes of this study, the term "international" denotes key news media with a strong international influence both in international health policy, funding and the global media. These media reach audiences beyond just one country. But although they were chosen carefully, they cannot be considered representative. Due to resource, time and language constraints some leading media organisations were excluded, such as the Reuters, AP, Wall Street Journal and foreign-language media such *Le Monde*, which has reported considerably on NDs. A direction for further study could be to study media coverage in these media.

7. RECOMMENDATIONS AND CONCLUSIONS

The HIV/AIDS epidemic unfolded a model for health advocacy which led to a social transformation of human rights and health. Advocates won battles on many issues, such as on policy, patients' rights, access to treatment and not least funding. The potential for health advocacy is thus enormous. It is not easy to find strong advocates for diseases affecting the poorest of the poor in developing nations. Yet a network of concerned individuals, PPPs and other groups could coalesce to form a potent voice on NDs in an increasingly politicised climate around global health issues.

Bringing NDs out of the dark will require planned advocacy; news stories should be powerfully and thoughtfully developed from the issues. Sustained advocacy, with a variety of messages for different audiences and media, rather than a one-off event, will be necessary to have real impact. In view of the findings of this study, the major recommendations for future advocacy work are as follows:

- Carry out a sustained, long-term advocacy campaign;
- Reorient public health agencies to raise priorities for advocacy;
- Actively engage the media and build relationships with interested journalists;
- Enlighten editors and foreign correspondents in the field about NDs;
- Build coalitions/ networks of voices on NDs (including PPPs and individuals);
- Seek to highlight developments in the field as news stories;
- Localise stories and/or find a broader context for a wider appeal;
- Bring in a "human face" and a visual picture of the diseases;
- Raise awareness in the general public on these issues;
- Find ways to keep a story moving forward;
- Seek alternative and innovative ways to promote ND reporting (such as grants) to address growing commercial constraints on foreign health coverage.

Neglected disease advocacy may be an uphill task, but it is slowly improving and opportunities for advocacy still remain. As David Brown of the *Washington Post* says: "There is a lot of potential for good news stories, in part because of the human faces associated [with NDs]." It is incumbent among public health professionals to bring these issues to public attention and the media. Otherwise, NDs will remain out of the public eye to fester unseen in impoverished communities.

8. APPENDIX 1: QUESTIONNAIRE FOR JOURNALISTS

Background

- Name:
- Sex:
- Media Organisation:
- Post and section of media org.: (eg. News reporter/ Features writer)

Health Reporting

1. How long have you been reporting on health?
2. What are the main health stories you report on? Are they mainly local stories?
3. Do you report on diseases outside of your locality, ie. international and tropical diseases? If so, which ones – TB, malaria, AIDS, bird flu?
 - How often? 1 or 2 x a month? Every few months? Once a year? Never?

Opinions on ND reporting

4. Do you think that NDs are an important health story?
5. Do you think the media has covered NDs adequately?
 - Agree/ Disagree/ Don't know
6. Do you think the media report excessively or disproportionately on some health problems, such as bird flu?
7. What do you think would improve coverage on NDs? (Celebrities, Gates, personal story?)

Personal reporting of NDs

8. Have you ever reported any story on NDs? (Include ALL NDs).
 - If not, why? / If so, which ones? Do you expect to report further on NDs?
9. What are factors that would make it unlikely that you report on NDs?
 - Eg. editors / readers interest? Story too boring?

Knowledge of NDs

10. Have you ever heard of these disease and how are they spread - African trypanosomiasis (tsetse), leishmaniasis (sandfly) and Chagas disease (kissing bugs, "triatones")?

Sources

11. Where do you get most of your information on diseases/ public health from?
 - WHO? DNDi? Local public health officials? Experts? Journals?
12. Do you think health experts are communicating adequately about the burden of NDs?

8. APPENDIX 2: SUMMARY ARTICLES FROM SEARCH

Date	Source	Headline
01/05/2007	Guardian	Repeat Prescription - United Front will take on diseases ravaging the world
27/10/2005	Guardian	Taking care of orphans - Scottish scientists doing what the pharmaceutical industry has chosen not to do
26/10/2005	Guardian	University hunts cure for parasitic infections
25/10/2005	Guardian	Tropical disease research gets 8m pounds funding boost
11/10/2005	Guardian	Cash plea to fight Africa's forgotten diseases that kill 500,000 a year
15/07/2005	Guardian	Scientists decipher DNA of diseases that threaten 500m of world's poor
04/07/2003	Guardian	Drive to get medical aid to poorest
18/02/2003	Guardian	Jean Pierre Garnier, head of Glaxo
28/07/2004	Guardian	World of Pain - The global reach of more adventurous travel brings exposure to a host of potentially fatal diseases
11/12/2003	Guardian	Dying of neglect
01/06/2007	Guardian	Climate change brings malaria back to Italy
02/01/2007	Guardian	Scientists on a mission to bring cheap drugs to the world's poorest countries
25/09/2006	Guardian	Waking the elephant
24/08/2006	Guardian	Destination: danger zone
03/01/2004	Guardian	Beautiful' disease which soon turns ugly
30/07/2003	Telegraph	The mystery of a very sleepy Sultan
16/05/2004	Telegraph	Pet passports lead to surge in dogs dying from foreign diseases
10/05/2003	Telegraph	British kidnap victim tells of jungle ordeal
09/05/2007	CNN.com/Reuters	Disfiguring skin disease plagues Afghanistan
30/03/2007	BBC	New low-cost vaccine for Africa
24/10/2005	BBC	Funding for tropical disease work
10/10/2005	BBC	Ignored diseases 'kill 500,000'
15/07/2005	BBC	Parasites' genetic code 'cracked'
09/10/2004	BBC	Drug hope for neglected disease
12/07/2004	BBC	Diseases forgotten in the wake of HIV
03/07/2003	BBC	Charity targets 'forgotten' diseases
19/07/2005	BBC	Waking up to Congo's sleeping sickness
15/07/2005	BBC	The disease that makes people zombies
26/08/2004	BBC	Kenya targets tsetse fly with radiation
23/04/2004	BBC	Test hope for sleeping sickness
09/12/2003	BBC	£1.5m for sleeping sickness cure
03/06/2003	BBC	Gene science targets sleeping sickness
03/02/2003	BBC	Scientists move against killer disease
01/04/2003	BBC	Working abroad: Other diseases
23/04/2004	BBC	Hope for tropical disease vaccine
23/12/2003	BBC	Killer disease hits south Sudan
08/03/2003	BBC	Pet passports let in diseases
25/04/2006	BBC	Thousands of blood donors refused
01/07/2004	BBC	None, only quote: "Doctors must decide whether the disease or its treatment poses the greater risk to patients"

24/05/2006	Time.com	None, under: Readers' Comments
11/02/2005	Time.com	How private groups step in for governments
31/07/2006	Time.com	Looking beyond "Trade vs. Aid"
17/04/2006	Time.com	A virtual classroom on global health
20/05/2007	New York Times	9th graders reach out to Sudan with Cash
31/07/2006	New York Times	A small charity takes the reins in fighting a Neglected Disease
07/04/2006	New York Times	Neglected diseases
26/07/2005	New York Times	A lab builds better barriers against invading parasites
20/03/2005	New York Times	He's got their number
24/04/2007	New York Times	Wiping out a parasite, not a spirit of adventure
12/09/2006	New York Times	Treating 'black fever'
19/08/2005	New York Times	Private-sector mercy
19/12/2004	New York Times	Column: Reading file
06/12/2003	New York Times	A region inflamed: Medicine: Hundreds of U.S. troops infected by parasite borne by sand flies, army says
28/10/2004	New York Times	White House of Horrors
14/12/2006	New York Times	Blood banks get new test to reveal fatal parasite
12/04/2005	New York Times	Lessons of the kissing bug's deadly gift
18/11/2003	New York Times	Rare infection threatens to spread in blood supply
29/03/2007	Washington Post	A dose of innovation - How to encourage the development of drugs for 'neglected diseases'
11/10/2006	Washington Post	In Brazil, field trails to treat world's poor. Private wealth fuels US-based project to create crucial hookworm vaccine
25/04/2006	Washington Post	Cure for ND: Funding. Large doses of donations will lead of new drugs, report says
15/02/2004	Washington Post	Disease spreads misery in southern Sudan: Location, war and poverty merge to give area the world's worst health care
03/03/2003	Washington Post	Science Notebook
13/01/2006	Washington Post	Bug repellent is key to going home well. Among the sick, fever is most common.
14/12/2006	Washington Post	Not really sympathetic, but does say one line about public health efforts in S.America to address housing
03/02/2004	Washington Post	FINDINGS
16/07/2005	Los Angeles Times	Three dangerous parasites share genetic code: The overlap could help spur drug development the three diseases the single-cell organisms cause
09/02/2004	Los Angeles Times	Nonprofits work with drug firms to treat diseases in third world
27/07/2006	Los Angeles Times	Private philanthropy shifts outlook of governments
25/10/2004	Los Angeles Times	A world of difference: A non-profit drug company works to wipe out disease that plagues developing nations but are ignored by Western pharmaceutical giants
24/10/2003	Los Angeles Times	Soldiers back from Iraq told not to donate blood for a year
15/03/2007	Los Angeles Times	Blood banks put at risk from parasite: 1 in 3,800 donors in LA area tested positive for Chagas, a deadly disease that is mainly found in Latin America
31/03/2005	Los Angeles Times	Drug shows promise against Chagas disease: An antifungal is reportedly successful in mice. The illness kills 50,000 people yearly.

14/07/2003	Los Angeles Times	Striving to keep pace with new outbreak of several new viruses and with future threats, health officials are scrambling to make blood transfusions safer
20/04/2007	Financial Times	Drug groups to donate medicines
30/11/2006	Financial Times	Free market must serve, not restrain, research
25/10/2006	Financial Times	WHO calls on German groups to donate drugs
25/05/2006	Financial Times	Patients' needs are what must drive drug research
11/03/2006	Financial Times	The casual-trousered philanthropists. The Bill & Melinda Gates Foundation is the world's largest charity and spends ore each year on health and education than the World Health Organisation.
13/01/2006	Financial Times	When noble ideas are no longer enough. Corporate Philanthropy: despite luring big pharm.co's back into research work to discover medicines to treat ND, wealthy donors have been criticised for losing focus, writes Jon Cohen
10/12/2005	Financial Times	Science Matters: the biter bit. Mosquito-borne malaria kills more than a million people a year, yet the fight against it has lacked urgency - until now
26/10/2005	Financial Times	University given Pounds 8m to create pioneering drugs
19/10/2005	Financial Times	Small groups are a solution. Neglected Diseases: Regulators must also help
22/10/2005	Financial Times	Let us focus on these significant killer diseases in developing nations
16/09/2005	Financial Times	An antidote to Neglected Diseases. Public-private partnerships: Alliances of drugmakers, governments and charities are reviving research into overlooked health problems, writes Andrew Jack
09/09/2005	Financial Times	Finance ministers launch global vaccine fund to tackle diseases of the poor
17/06/2005	Financial Times	Rich world divided over health of poor: The Bill and Melinda Gates Foundation, Medicins sans Frontieres and Gordon Brown represent just there of the differing approaches on how best to find cures for mass killer diseases, writes Andrew Jack
10/06/2005	Financial Times	How to spend 400m on medical research. Charity Management: Mark Walport, head of the Wellcome Trust, explains the priorities and concerns of the powerful global charity to Andrew Jack.
28/04/2005	Financial Times	ND gets shot in arm: Philanthropists encourage study of illnesses once seen as unprofitable, says Andrew Jack.
25/02/2005	Financial Times	Time to reject the neglect of lethal diseases: A worldwide initiative is funding medical research to find drugs for forgotten diseases in developing countries, writes Andrew Jack
25/01/2005	Financial Times	An aspirin for Juely is no longer good enough: As the battle against malaria gets under way, rare diseases await action from African nations, drug companies.
15/07/2005	Financial Times	Scientists crack deadly parasites' gene codes
26/06/2003	Financial Times	Partners target killer diseases the west ignores
10/09/2005	Economist	A promising prognosis
18/06/2005	Economist	Alternative medicine
14/04/2005	Economist	Halte and Healthy: A new way of developing drugs for neglected diseases of the poor world
28/05/2006	Agence France Presse	WHO assembly backs talks on 'neglected' disease research

16/05/2006	Agence France Presse	Kenya, Brazil press for funds for neglected diseases
08/06/2005	Agence France Presse	Nobel winners back global appeal for research into neglected diseases
03/07/2003	Agence France Presse	MSF, partners to develop drugs for neglected tropical diseases
07/05/2003	Agence France Presse	Researchers, scientists conference on drugs for "neglected" diseases to open in Nairobi
08/05/2003	Agence France Presse	Pharmaceutical giants urged to address diseases of poor
09/05/2003	Agence France Presse	Health experts urge big pharma to relax patent laws
10/10/2006	Agence France Presse	WHO and Sanofi-Aventis renew \$25m disease cooperation
26/08/2005	Agence France Presse	Epidemic of sleeping sickness spreading in Uganda: study
22/06/2005	Agence France Presse	Microsoft founder Gates boosts sleeping sickness vaccine research
03/02/2004	Agence France Presse	Sleeping sickness threatens a third of Angola's population
20/02/2003	Agence France Presse	Trypanosomiasis one of the scourges of Africa's health, development
13/08/2006	Agence France Presse	Rare parasite-borne disease kills six children in northern Kenya
05/07/2005	Agence France Presse	Rare outbreak of leish.kills more than 150 in northern Ethiopia
18/05/2005	Agence France Presse	India, Nepal, Bangladesh, strike deal to fight deadly fly-borne disease
10/11/2004	Agence France Presse	Hundreds of US soldiers in Iraq hit by parasite that causes chronic sores
22/12/2003	Agence France Presse	MSF urges faster action against spread of kala-azar in south Sudan
21/01/2003	Agence France Presse	German activists blast "shocking" situation in Iraq due to UN embargo

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