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Adam Joseph Weiss Date

WHAT IT MEANS TO BE GUINEA WORM FREE IN GHANA: AN INSIDERS ACCOUNT FROM NORTHERN GHANA

BY

Adam Joseph Weiss

Degree to be awarded: M.P.H.
Masters of Public Health
Executive MPH

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BY

Adam Joseph Weiss
Emory University, MPH, 2015
B.A., Ripon College, 2003

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Abstract

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Despite several periods of stagnating Guinea worm incidence in Ghana through the 1990s and early 2000s, the last reported case of Guinea worm disease (GWD) was in May 2010. In July 2011 Ghana celebrated the interruption of Guinea worm transmission. While it has been established that Guinea worm (GW) causes disability, pain and socio-economic hardship, there is a dearth of population-based evidence collected in post GW endemic countries to document the value attributed to GWD eradication by residents in formerly endemic communities. Given Ghana's recent history of GWD and a concentrated burden of disease in the Northern Region, a phenomenon which remained true through to the final cases of the campaign, seven villages in the Northern Region were targeted for a retrospective, cross-sectional, descriptive and historical study to detail the perceptions, attitudes and beliefs about the impact of eradication of GWD in Northern Ghana. The study revealed that respondents from the sampled communities felt GW eradication served as an impetus for improved socio-economic conditions as the impact of infection prohibited the pursuit of individual and social advancement. Of the 143 respondents, 133 had experienced GWD, with incapacitation averaging six-weeks per GW event. Each respondent was infected nearly four separate times in their lifetime.

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N'a soha, amazara!

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List of Abbreviations

CDC	Centers for Disease Control and Prevention
EU	European Union
GWD	Guinea Worm Disease
GW	Guinea worm
GWEP	Guinea Worm Eradication Programme
GGWEP	Ghana Guinea Worm Eradication Programme
ICCDE	International Commission for the Certification of Dracunculiasis Eradication
IDWSSD	International Drinking Water Supply and Sanitation Decade
IMRaD	Introduction, Methods, Results and Discussion
NTDs	Neglected Tropical Disease
TCC	The Carter Center
UNICEF	United Nations Children Fund
WHA	World Health Assembly
WHO	World Health Organization

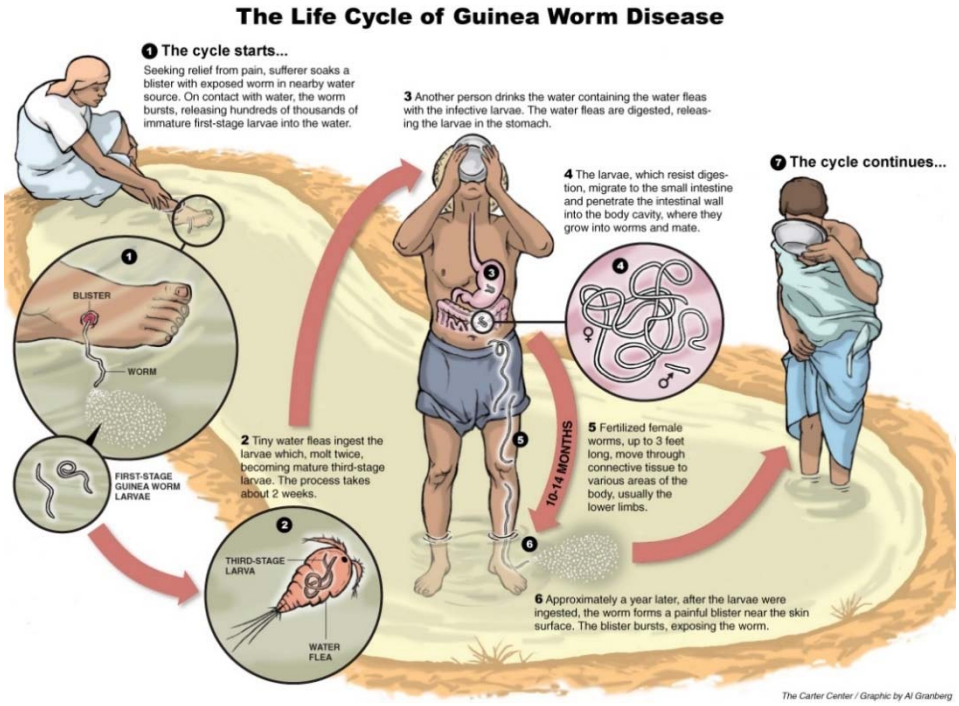
Chapter 1: Introduction

On the heels of eradicating smallpox, the global campaign to eradicate *Dracunculiasis medinensis*, commonly known as Guinea worm disease (GWD), was conceived by staff of the United States Centers for Disease Control and Prevention (CDC) in October 1980 (Hopkins, et al., 2008). It was originally identified as a sub-goal of the International Drinking Water Supply and Sanitation Decade, and was envisioned to serve as an indicator of successfully providing access to potable water (1981-1990) (CDC, 2014). Despite the launch of the World Health Organization (WHO) Collaborating Center for Research, Training and Control of Dracunculiasis in 1984 at the CDC, the World Health Assembly (WHA) did not adopt a resolution calling for the "elimination" of Dracunculiasis until 1986. At that time there were an estimated 3.5 million cases annually in 20 countries in Africa and Asia and 120 million persons were at risk for the disease (CDC, 2005).

Guinea worm disease is a nematode parasite that generally only affects human beings (Hopkins & Hopkins, 1991; Muller, 1971). Also known as the *fiery serpent* because of the generalized burning sensation one feels when the worm is about to emerge, GWD is referenced in the bible and has been recovered from mummies from Ancient Egypt nearly 3,000 years old (Hopkins & Hopkins, 1991). Humans become infected with GWD by drinking stagnant water containing water fleas (copepods) that ingested Guinea worm (GW) larvae (Fedchenko, 1897). The ingested larvae undergo a series of developmental processes inside the human host and reach maturity approximately three months after infecting the host. Mating occurs at this stage, with males dying shortly thereafter. The impregnated female continues to develop and migrate towards a point of emergence, generally in the lower part of the body, approximately 9-14 months after ingestion. As the worm nears the skin's surface, the immune system recognizes the foreign object and the skin swells forming a blister. Once the blister breaks, usually as a result of scratching or

cutting the blister due to burning, itching and pain, a lesion is exposed with the emergent worm poised to release its larvae. Transmission requires a person with an emergent GW to enter a stagnant water source, enabling the worm to release its larvae in hopes to continue its lifecycle (see Figure 1).

Figure 1: The life cycle of Guinea worm disease



Guinea worm disease has a low mortality rate but causes marked morbidity and imposes a significant negative economic impact on affected villages (Hopkins and Hopkins, 1991; Greenaway, 2004; Ruiz & Hopkins, 2006). There is no drug or vaccine to combat GWD and principle diagnoses are only made after the painful emergence of the worm (Hopkins and Hopkins, 1991; Kim and Ruiz, 1997). Persons who contract *D. medinensis* infections do not develop immunity (Hopkins, et al., 2002a).

Disease eradication

Eradication has been defined in various ways, but is best described by Andrews and Langmuir as 'the purposeful reduction of specific disease prevalence to the point of a continued absence of transmission within a specific area' (1963). The first human diseases to be targeted for eradication were hookworm and yellow fever in the early 20th Century (Dowdle and Hopkins, 1988). Although eradication efforts were unsuccessful, due to a limited understanding of the parasites' biology, hookworm and yellow fever, alongside later targets of malaria and yaws, set the stage for further deliberations on the concept and efficacy of eradication.

Inspired by the successful eradication of smallpox in 1977, the International Task Force for Disease Eradication was formed at The Carter Center in 1988 to evaluate disease control and prevention and the potential for eradicating other infectious diseases. Scientists and notable international health organizations serving on the task force identified eight diseases that could potentially be eradicated, they include: Guinea worm (dracunculiasis), poliomyelitis, mumps, rubella, lymphatic filariasis, cysticercosis, measles, and yaws (CDC, 1993).

Criteria for disease eradication

Scientific feasibility and political support are the two primary factors determining whether a disease can be eradicated.

Conditions that make it scientifically feasible to eradicate a disease include:

- Epidemiologic vulnerability. A disease could be considered vulnerable if it does not spread easily; if there is a natural cyclical decline in prevalence; if there is a naturally induced immunity; if it is easily diagnosed; and if the duration of any relapse potential is short.
- Availability of an effective and practical intervention. Such interventions could include a vaccine or other primary preventive measure, a curative treatment, or a means of eliminating vectors. Ideally, intervention should be effective, safe, inexpensive, long-lasting, and easily deployed.

- Demonstrated feasibility of elimination. A disease that has been documented to have been eliminated from an island or other geographic unit could be a candidate for eradication.

Even if it is scientifically feasible to eradicate a disease, there are nonscientific conditions that must be considered, such as:

- Perceived burden of the disease
- Expected cost of eradication
- Synergy of eradication efforts with other interventions
- Necessity for eradication rather than control

Eradicating Guinea worm

Guinea worm disease was identified as biologically and technically feasible to eradicate. The natural history of GWD has been described above and it has no known animal reservoir and no human carrier state beyond the 1-year incubation period (Hopkins and Hopkins, 1991; Alyward, et al., 2000; Molyneux, et al., 2004). Therefore, there is no known opportunity for the disease to return after the last human case is eliminated. GWD is easily diagnosed because of its unique clinical presentation. Guinea worm is well-known and recognized by the general population that it usually has its own unique name in the local languages of endemic areas. The ease of diagnosis and the seasonal occurrence of GWD make it easy to identify thereby facilitating disease surveillance and intervention activities. Prior to the WHA resolution to eradicate this disease, GWD had already been deliberately eliminated from parts of the former USSR during the 1920s and from endemic areas of Iran in the 1970s.

Since the WHA resolution in 1986, the transmission of GWD has been eliminated from 17 of the then 21 endemic countries (Hopkins, 2013). Asia and the Middle East no longer experience GWD, currently it only remains endemic to South Sudan, Chad, Mali and Ethiopia. The progress experienced by the global eradication campaign reveals the effectiveness of focused community-

based surveillance, health education, case containment, water filtration and copepod control using a *temephos larvicide*. Between January and August 2015, there were only 15 cases of GWD reported in the four endemic countries (The Carter Center, 2015).

Certification of eradication

GWD transmission is interrupted in a country when no new GWD cases occur for 12 consecutive months (i.e., one incubation period). At that point, a country may apply for certification of GWD-free status from the International Commission for the Certification of Dracunculiasis Eradication (ICCDE). The ICCDE is a panel of international GWD specialists. It was established by WHO in 1995 to verify and confirm information from countries applying for certification. The ICCDE considers GWD eradication achieved in a country when:

- Adequate active surveillance systems have confirmed the absence of GWD for 3 or more years
- A rumor log of suspected cases has been maintained for a 3-year period detailing:
  - The particulars of each case
  - The origin of each case
  - The final diagnosis of each case (i.e., a true case of GWD or some other condition?)
- All confirmed cases imported from endemic countries have been traced to their origins and have been fully contained

The ICCDE certifies a country as being free from GWD after it confirms these criteria have been met and receives a report detailing the history of GWD in that country (WHO, 1996).

Guinea worm disease eradication in Ghana

The Ghana Guinea Worm Eradication Program (GGWEP) started in 1989 with a nationwide case search reporting 179,556 cases of GWD (Department of Health and Human Services, 1990; Cairncross, et al., 2012). Ghana reported the second highest documented incidence of GW only to Nigeria, which reported more than 650,000 cases in 1988 (Department of Health

and Human Services, 1990; Edungbola, et al., 1992). In 1989, Ghana documented a concentrated burden of the disease in the Northern Region, a phenomenon which remained true to the final cases of the campaign (Cairncross, et al., 2012). The Northern Region shares boundaries with the Upper East and the Upper West Regions to the north, the Brong-Ahafo and Volta Regions to the south and two neighboring countries, the Republic of Togo to the east and Côte d'Ivoire to the west. Nearly all of the socio-economic and health indicators in the region rank between eighth and tenth out of the ten regions, and are all lower than the national average (Ghana Statistical Service, 2013). The region also has a relatively small population (1,820,806) spread over a large land area of 70,000 KM^2 (see Figure 2). Most of the communities are rural with limited accessibility due to difficult terrain. The people of the Northern Region are primarily subsistence farmers and practice small-scale animal husbandry. The region experienced repeated internal conflict throughout the mid-1990's, including the well-referenced 'Guinea Fowl War', which led to an exodus of health workers and a reduction in the provision of health services, including interventions aimed to eradicate GWD (Cairncross, et al., 2012; Jonsson, 2007; Assefa, 2001). These challenges, together with a long dry season (November to April) and difficulties in extracting ground water, aided the transmission of GW.

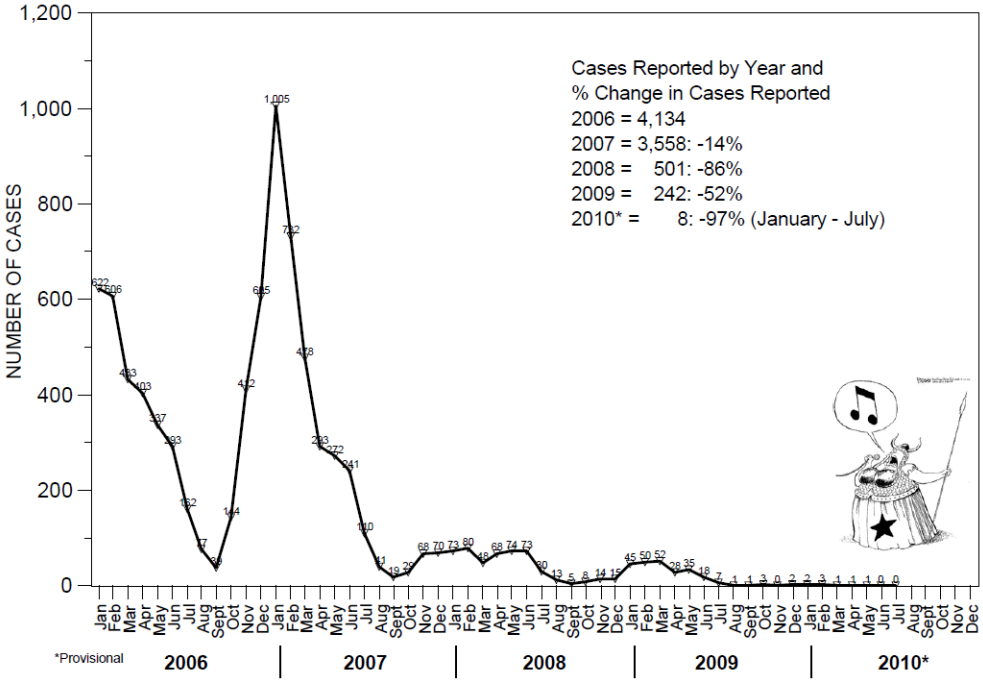
Figure 2: Map of Ghana

Source: *http://www.ezilon.com/maps/images/africa/political-map-of-Ghana.gif*

Despite several periods of stagnating GW incidence in the 1990's and early 2000's, persistent community-based interventions and renewed political will helped Ghana realize its last case of GWD in May 2010 (see Figure 3) (Cairncross, Tayeh & Korkor, 2012). Having successfully observed 14-months of zero case reports by July 2011, Ghana was able to celebrate the interruption of Guinea worm transmission (The Carter Center, 2011). Although GWD no longer exists in Ghana, the GGWEP remained responsible for activities related to certification efforts. Such activities included: country-wide sensitization about a cash reward (~100USD) for detecting or reporting someone with GWD, collection of health facility reports on GWD, and the investigation of rumors of GWD. Following three years of zero case reports, the GGWEP submitted a comprehensive country report to the ICCDE and WHA to support a request to be

certified free of GWD. In January 2015, Ghana was granted certification by the WHO (WHO, 2015).

Figure 3: GGWEP-Number of Reported Cases of Dracunculiasis: 2006 - 2010



Source: CDC, 2010

Significance, Rationale and Aims

Ghana's recent success serves as a reminder of the global eradication campaigns collective achievements since its inception in 1980, having attained a 99.9% reduction in disease incidence. Public health literature about disease control, elimination and eradication programs by D.A. Henderson, Stephen Cochi and others archive the trials and tribulations overcome (and still faced) to reduce the burden of disease (Aylward, et al., 2000; Pray et al., 2002). While the tenants of public health require that programs and interventions meet the needs of the intended beneficiaries, post-intervention literature generally highlight high level programs outputs, forgoing documentation of local perceptions. Although the Guinea worm eradication program has been successful across 17 countries, a holistic understanding of the legacy of eradication cannot be fully

appreciated without an appraisal of what the achievement meant to the communities that suffered from GWD.

The aim of this study is to understand the attitudes and perceptions of Ghanaian's following the eradication of GWD, through household surveys and focus group discussions, and to document the value attributed by residents of the Northern Region. Additionally, the study will:

- Assess the level of awareness about GWD and the cash reward for reporting a case (or suspect case) of GWD
- Document and report any rumor reports of Guinea worm disease

Journal Selection

The topics discussed in this paper are international health, community-based public health programming, and disease eradication in the developing world. These subject areas require a journal that focuses on similar issues and has a readership engaged in them. The journal selection process began with a thorough review of journals that specialize in the aforementioned topics, and took into consideration the journals' audience, prestige and impact factor. The journal targeted for publication is the Journal of Epidemiology & Community Health. Key components required by the journal are based on the IMRaD style (i.e. Introduction, Methods, Results and Discussion). Additional criteria for review by the journal include:

1. No more than 3,000 words
2. Abstract of no more than 250 words
3. Indicate what is already known on the subject and what this study adds to that field of available knowledge
4. Conform to the Declaration of Helsinki
5. Number of tables, illustrations or graphics up to 5
6. References up to 40

The manuscript intended for submission to the Journal of Epidemiology & Community Health can be found in Chapter 5.

Chapter 2: Literature Review

The value of disease control and eradication efforts ought to be self-evident, but since the launch of the first eradication initiative in 1915, each have been subject to great debate (Andrews and Langmuir, 1963; Dowdle, 1998; Aylward, et al., 2000; Miller, et al., 2006; Klepac, 2013). Even the oft lauded campaign to eradicate smallpox was not without its adversaries. In 1953, the first director-general of the WHO failed to convince member states attending the WHA to tackle smallpox, though it was later adopted in 1959. The global effort to eradicate GW endured similar challenges, though less about its feasibility than a general absence of political will among member states (CDC, 2014). The pre-eminent D.A. Henderson, a key proponent of smallpox eradication, capitulated that GW would be eradicated in the near future, though he qualified that the context was more challenging than that of the smallpox campaign (Miller, et al., 2006).

Guinea worm disease is deemed the disease of the forgotten people, because those with GW are from the most remote areas of the world, and are among people often disenfranchised from their government (CDC, 2014). Although now categorized as a Neglected Tropical Disease, which has brought new interest and funding, the GW campaign lacked coordination and funding from 1980-1986. However, in 1986, former US President Jimmy Carter agreed to have The Carter Center be the lead agency for the eradication efforts. As new resources were made available to begin implementing country-wide interventions to eradicate GWD, there was a marked increase in the publication of scientific articles on the subject.

Key literature searches were conducted through PubMed, EBSCOhost and GoogleScholar databases. Search queries included combinations of the following key words, “perception, beliefs, views, eradication, elimination, control, legacy, and implications”. Additional resources were obtained from the Carter Center Guinea Worm Eradication program archives and website. Past

and recent research about GW often focuses on the risks associated with eradication, economic impact, operational mechanisms, political will, and lessons learned (Hopkins, 2013). In addition, a myriad of research has been conducted on GW's molecular structure, lifecycle, and epidemiology since the late 1800's (Fedchenko, 1897; Muller, 1971; Belcher, et al., 1975; Muller, 1979; Hopkins, 1983; Smith, et al., 1989; Watts, Brieger, & Yacoob 1989; Imtiaz, Hopkins, & Ruiz-Tiben, 1990; Hours & Cairncross, 1994**;** Kim, et al., 1997). Each of these aspects are valuable to the refinement of existing programs and the development of new programs, but discussions often become entangled in policy issues. Fortunately, specific literature about the culture and people of the Northern Region, including perceptions of western medicine are widely accessible (Bierlich, 1995). Several studies also detail the financial implications of GWD in similar environments across both Ghana and Nigeria (Kim, et al., 1997; Bierlich, 1995; Belcher, 1975). The Ghana and Nigeria studies helped frame the eradication campaign and their findings supported the refinement of interventions and continued investment by partners.

While the literature includes all of the aforementioned topics, there is only one study that focused on local perceptions (Bierlich, 1995). The global eradication campaign was designed to alleviate pain and suffering and as noted by other researchers, the Guinea Worm Eradication Program (GWEP) has emphasized the need for sustained dialogue with the beneficiaries and actors (Miller, et al., 2006; Atkinson, et al., 2011). Despite being grounded in community level surveillance, there is no population-based evidence documenting the value attributed to GWD eradication by residents in endemic communities, either in a pre or post-eradication environment. This study was designed to understand the attitudes and perceptions of Ghanaian's following the eradication of GWD and expand the literature to accommodate what it means to be Guinea worm free in Ghana.

Chapter 3: Data Collection, Analysis and Results

Materials and Methods[1]

The study was retrospective and cross-sectional as it detailed perceptions, attitudes and beliefs about the impact of eradication of GWD in Northern Ghana. Due to the dearth of literature about attitudes towards GWD in Northern Ghana, house-to-house surveys and focus group discussions were conducted. Furthermore, the investigators utilized a concurrent strategy design, with the survey tools capturing demographic data and direct and indirect experiences with GW simultaneously (Hewson, 2006). Prior to implementation, a pilot test of the survey instrument was conducted within a sub-section of Tamale town. The sample represented the same demographic targeted in the study and pilot confirmed the reliability and validity of the survey tools. In addition, the pilot helped to improve the logistical planning required to conduct interviews across the seven villages.

Village Selection

Due to the historically high incidence of GWD in the Northern Region and the unique occurrence of GW in urban settings (not observed in other countries), the study targeted both urban and rural communities to generate an understanding of perceptions in both environments (see Table 1). The urban towns of Saveulgu, Diare and Fufulso Junction were surveyed in addition to the more remote, smaller villages of Gburimani, Wantugu, Issape and Gushie. The communities were all in the Northern Region and represented both the Dagomba and Gonja ethnic groups, the two most heavily GWD burdened ethnic groups in Ghana.

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[1] *Ethical Issues*
Prior to the study's implementation, the project proposal and study tools were submitted to the Emory University Institutional Review Board (IRB) for review. The IRB determined that the study did not require IRB review. In addition the Ghana Ministry of Health approved the study as operational research and required no further review or approval.

Table 1: Guinea Worm Case History

Village Name	Population (*2009*)	No. of Cases 2005	No. of Cases 2006	No. of Cases 2007	No. of Cases 2008	No. of Cases 2009	No. of Cases 2010	No. of Cases 2011
Savelugu	43,234	80	411	1,364	83	14	0	0
Diare	13,836	120	298	310	50	12	4	0
Fufulso-Junction	5,524	0	0	1	10	120	0	0
Gburimani	2,525	81	11	30	1	1	0	0
Wantugu	4,426	77	236	122	22	4	0	0
Issape	520	8	7	10	2	3	0	0
Gushie	1,270	5	11	40	11	0	0	0
TOTAL	**71,335**	**371**	**974**	**1,877**	**179**	**154**	**4**	**0**

The study targeted a minimum of 30 households to interview and five focus group discussions to conduct in each of the three towns (Savelugu, Diare and Fufulso Junction). In the four smaller communities (Gburimani, Wantugu, Issape and Gushie) a minimum of 5-20 interviews and 2-3 focus groups were targeted. In the communities where schools were present (i.e., Savelugu, Diare, Fufulso Junction, Gburimani, Wantugu and Gushie) at least one focus group was targeted in a school setting.

A staff member of the Ministry of Health/Ghana Health Service provided translation to and from English into Dagbani and Gonja for the interviews. A handheld tablet was used to collect the quantitative data (i.e., GPS coordinates, demographics, etc.) and paper questionnaires were used to record responses to open ended questions. To ensure the accuracy of the transcription, interviews were audio recorded and transcribed daily.

Household and Participant Selection

To ensure random selection of household participants, the investigator went to the center of the targeted village, spun a bottle, and proceeded in the direction of the bottle to the first house encountered. In each household the head of household (or representative) was selected to be interviewed (see Appendix 10: *Household Interview Tool*), and was read the verbal consent form

(see Appendix 12: *Verbal Consent Script*) to ensure the respondent was adequately informed of the nature and substance of the interview. If consent was provided, the investigator further inquired if the interview could be digitally recorded. Upon approval, a private location was identified to ensure privacy and prevent potential bias. After completing the first interview, a second interview was conducted with another member of the same household.

If the head of household never had GWD, the interview was still condcted. However, when the second participant was identified, the investigator attempted to select a member of the household that previously had GWD. If no individual previously had GWD, the investigator attempted to conduct an interview with a household member above 19 years of age. If no one above 19 years was available, the investigator selected a second interviewee 19 or younger. When possible, the investigator attempted to conduct the household interviews with one male and one female. If only a group of children were present, the investigator conducted a focus group (see Appendix 11: *Focus Group Interview Tool*) instead of a household interview.

After surveying the household, the investigator spun the bottle again to identify the next household and followed the same participant selection process. To minimize the clustering of households, the interval between houses was determined based on the size of the village. In smaller villages, the first house in the direction of the bottle was visited, while the second or third house was selected in an urban town. In villages with populations between 500 and 4,000, 5-20 household interviews were conducted (see Table 2), and in larger villages, 4,001-44,000, at least 30 households were selected. When possible, interviews were conducted in a private setting, either in the respondent's home or in a structure that minimized outside influence.

Focus Group Selection

In addition to household interviews, focus group discussions were conducted to ensure that perceptions across demographic groups were obtained (see Appendix 11: *Focus Group Interview Tool*). Focus group discussions captured input from the following age groups: 5-18, 19-35, 36+ years old. As previously noted, if a household only comprised of children, a focus group survey was conducted. Schools were also targeted for focus group discussions, thus addressing a portion of the 5-18 year-old cohort not explicitly targeted during the individual household interviews. During discussions the investigator ascribed comments to approximate age and sex of the respondent to simplify the summation of responses.

Table 2: Targeted and implemented surveys

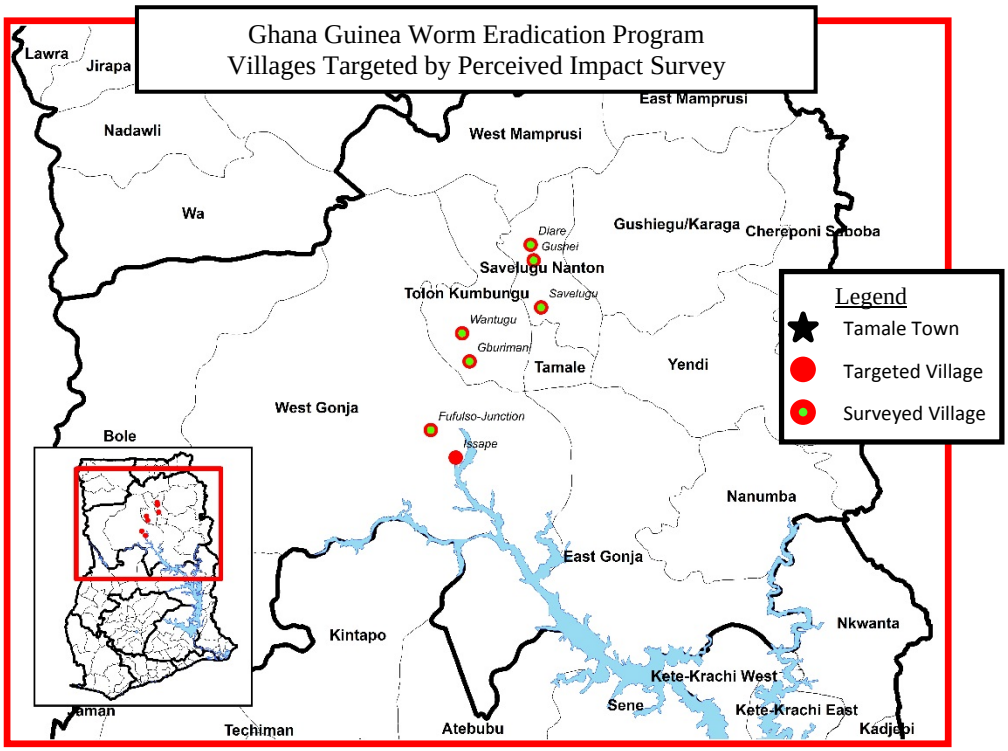
Village Name	Population (*2009*)	No. of Households	No. of Household Surveys Targeted	No. of Household Surveys Conducted	No. of Focus Groups Targeted	No. of Focus Groups Surveyed
Savelugu	43,234	4,323	30	30	10	3
Diare	13,836	1,383	30	30	7	3
Fufulso-Junction	5,524	552	30	32	5	3
Wantugu	4,426	442	20	20	3	2
Gburimani	2,525	252	10	21	2	3
Gushei	1,270	127	7	10	2	2
Issape	520	52	5	0	2	0
TOTAL	**71,335**	**7,131**	**132**	**143**	**31**	**16**

The investigator met with district health officials and community chiefs as part of the community entry protocols and was consistent in the administration of each question to preserve the integrity and consistency throughout implementation (Russell, 1988). Permission to conduct and record interviews was obtained from all respondents. According to local regulations, the headmaster can provide consent to discuss GWD, though general consent amongst the students was requested and anyone electing not to participate was not be obligated to do so.

Results

A total of 143 head of household interviews were conducted in six of the seven targeted towns and villages (see Figure 4). Issape, in the Central Gonja District, could not be visited due to inaccessibility caused by heavy rains. In addition, 18 focus group discussions were conducted capturing 400 residents across all age-groups, including two schools in Tamale town, capital of the Northern Region.

Figure 4: Map of communities targeted and surveyed



Source:GHS/MOH/GGWEP

Of the individual respondents, 74 were male and 69 were female, with generally equitable distribution across the 16-25, 26-50 and 51+ years age groups (see Table 3). Farming and housewifery were the two dominant occupations, representing 70 and 52 percent of the male and female respondents respectively. Although most of the housewives also actively participated in farming activities, only their first response was analyzed as it reflects their primary occupation.

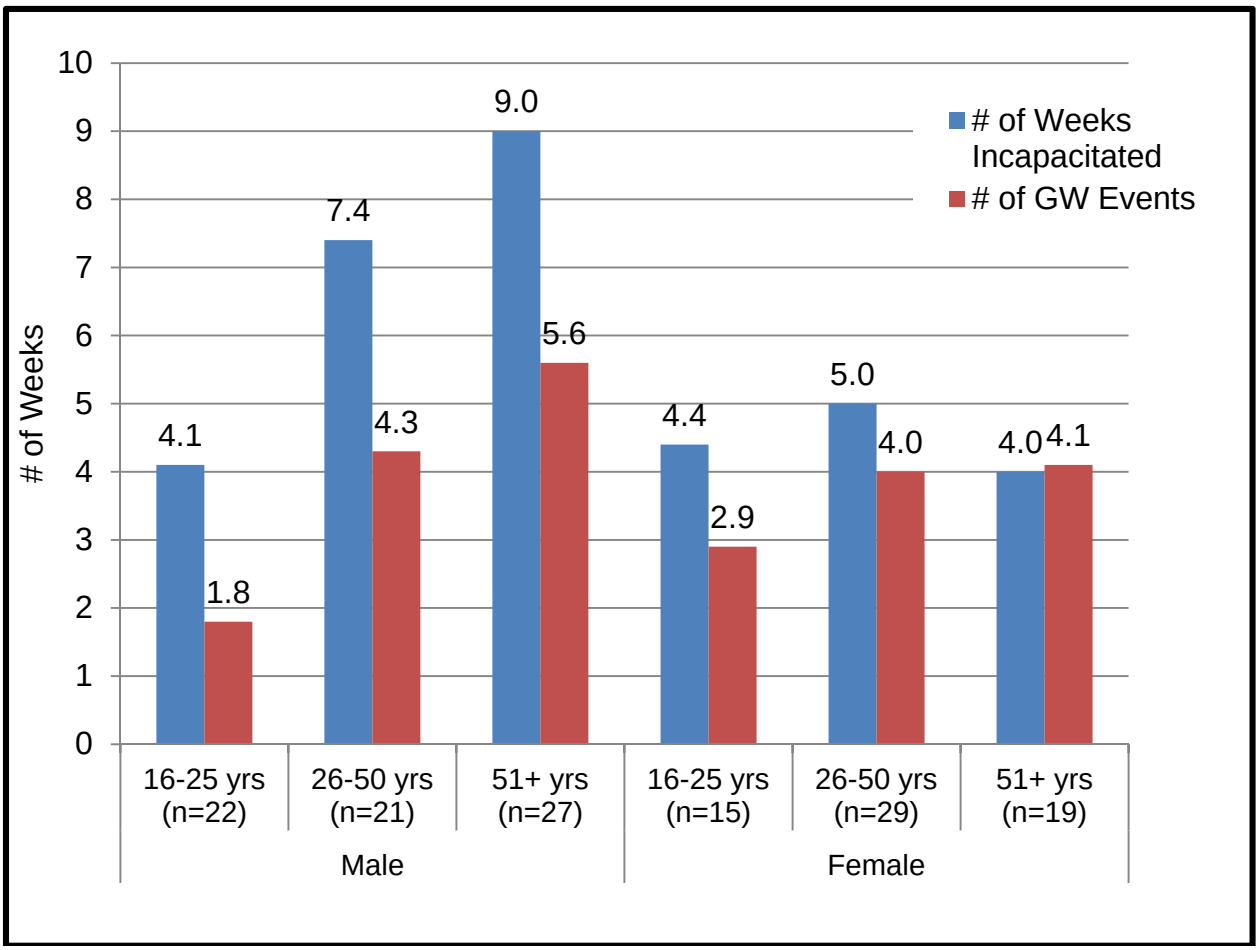
Table 3: Personal Experience with GWD of 143 Individual Respondents

	Number	Number Ever had GWD	Average Years Since Last Infection of GWD (Range)	Average Number of GWs in Lifetime (Range)	Average Number of Times GW Emerged During Lifetime (Range)	Average # of Weeks Incapacitated (Range)
Individual Respondents						
ALL	143	133	11.9 (2-60)	7.3 (1-75)	3.9 (1-30)	5.8 (1-52)
Age Profile						
Male	74	70	13.9 (1-60)	7.2 (1-40)	4 (1-20)	6.5 (1-52)
16-25	22	22	9.1 (2.5-22)	2.9 (1-6)	1.8 (1-3)	4.1 (1-12)
26-50	22	21	12.1 (3-30)	8 (1-35)	4.3 (1-15)	7.4 (0.5-52)
51+	30	27	19.3 (1-60)	9.4 (1-40)	5.6 (1-20)	9 (1-52)
Female	69	63	9.7 (3-45)	7.7 (1-75)	3.9 (1-30)	4.5 (1-20)
16-25	16	15	6.1 (3-10)	6.7 (1-30)	2.9 (1-10)	4.4 (1-12)
26-50	33	29	11.6 (3-40)	7.7 (1-75)	4 (1-30)	5 (2.5-20)
51+	20	19	9.6 (2-45)	7.6 (1-35)	4.1 (1-10)	4 (1-8)

Of the 143 respondents, 133 claimed to have experienced GWD at least once in their lifetime. On average, respondents had nearly four GW events (separate occurrences of GWD, not multiple worms at one time), and seven worms in their lifetime (see Figure 5). Ninety-seven percent (129/133) of the respondents were incapacitated for an average of six weeks during their most recent exposure to GW. Several respondents indicated they were incapacitated for an entire year due to complications resulting from secondary infections and having multiple worms emerge throughout the year. Two male respondents reported they were incapacitated for one year due to multiple worms. Females reported fewer worms and shorter periods of incapacitation. Occupation did not reveal any significant difference in number of GW events or duration of incapacitation. Only 35 percent (46/133) of the respondents indicated they reported to a village volunteer or health facility. All respondents who had GWD reported scarification at the location of worm emergence. Three percent (4/133) of the respondents indicated continued pain associated with the area where

the worms emerged and 1.5 percent (2/133) reported persistent difficulty ambulating due to related infections. This is consistent with studies highlighted by Imtiaz, Hopkins and Ruiz (1990).

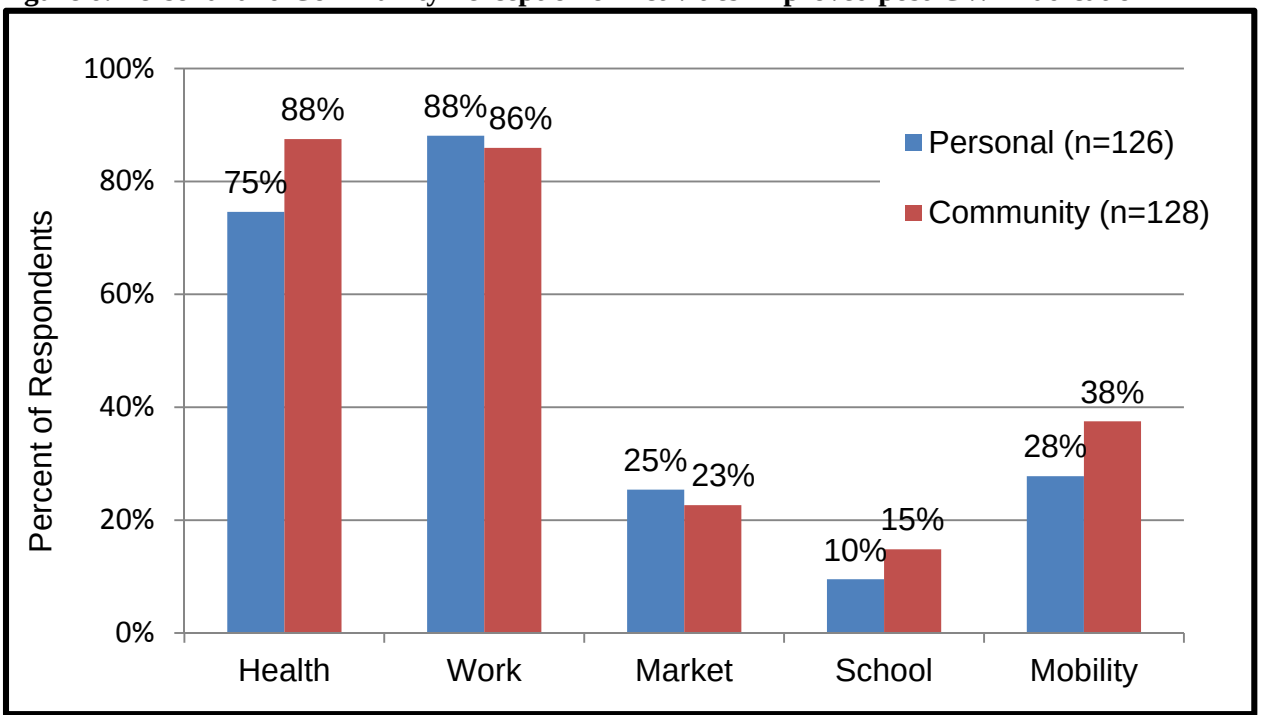
Figure 5: Average Number of Weeks Incapacitated/GW Events



All 143 household respondents indicated that the absence of GW had changed their life, both individually and as a community. Results from open-ended questions about how and in what ways the absence of GW impacted their lives individually revealed that between 75 and 88 percent of respondents believed health and work (i.e. farming, business, household chores, etc.) improved significantly (See Figure 6). More males cited improved farming first, whereas females answered improved health. All female respondents that cited improved market and work also mentioned the ability to focus more time and attention to small business and trading activities. Similarly, all the men indicated an increase in productivity from farm labor (and not losing entire harvests).

Although health and work were principal areas of improvement, between 10 and 38 percent of respondents also noted improved mobility, market activities and school attendance. Similar themes were acknowledged at the communal level, however, there was a slight increase in health and mobility improvements from a communal perspective compared to the individual perspective. There was no distinguishable difference between Dagomba and Gonja respondents.

Figure 6: Personal and Community Perception of Activities Improved post-GW Eradication



In addition to individual interviews, 18 focus group discussions were held (including 6 school focus groups), with a total of 400 participants. The primary themes identified by the groups were consistent with those of the individual interviews and included health, work, economics and school performance. More than 90 percent of the focus groups identified work as the primary activity impacted by GWD and referenced the impact as being more significant at the community level. Overall, 99.8 percent of respondents (542/543) expressed that GWD had a negative impact on their lives and that they had experienced improvement in their livelihood post GW eradication.

While not a focus of the study, respondents were also asked if they had seen GWD within the past two years (the period when zero cases were reported by the GGWEP). Three people claimed to have had GWD in 2012 and one person in 2013. The most recent rumor had been reported to the village volunteer, who confirmed it was not GWD. All other alleged rumors were recorded and investigated by the GGWEP and each was confirmed not to be GWD.

Limitations

The methodology applied in the study was limited in several ways. Recall bias may have been an inherent limitation, particularly given the average 12-year gap since the most recent experience with GWD. This could potentially skew the study's findings by over or understating the perceived changes post-GW eradication. The themes addressed by respondents were sincere as they were consistent with the impact and effects associated with a physically incapacitating disease. Respondents provided general accounts of their experience with GW, but there is no baseline data to compare their perceptions prior to the eradication of GW. Ghana's economy has grown significantly over the past decade, which could have also influenced respondents, but much of the responses focused on physical inputs and not on variables influenced by macro-economic conditions (e.g. increased value of maize, shea nuts or external investment).

Chapter 4: Discussion

Although the elimination of a public health problem is in itself the definition of success, this study provides an account of how the eradication of GWD was perceived in Ghana. This survey is the first known attempt to collect population-based evidence from a post GW endemic country to document the value attributed to GWD eradication by residents in formerly endemic communities.

The study showed that 97 percent of the respondents were incapacitated and were unable to carry out their normal duties for an average of 6 weeks. This is also consistent with the 6-15 weeks of incapacitation reported in previous studies (Kim, et al., 1997; Watts, et al., 1989; Belcher, et al, 1975). The study also showed that the duration of incapacitation was longer for people over 25 years. This represents the adult working cohort, who by virtue of their responsibilities, drink more unsafe water outside of the household, and are thereby at higher risk for acquiring the disease. Since farming is the main occupation for most of the respondents and infection of the disease is most prevalent during the farming season (May to October), incapacitation had a direct impact on agricultural productivity. Furthermore, as identified by other researchers, children also missed school either because they were incapacitated by the disease or as a consequence of replacing sick relatives in agricultural activities (Karam & Tayeh, 2006). Nearly all respondents specifically mentioned that GWD resulted in lost crop production, a loss of dignity, and economic and social hardship not only in the last decade, but as far back as their oral histories could recount.

The study also asked respondents if they had observed the existence of GW in the past two years. Three people claimed to have GWD in 2012, though all were confirmed not to be consistent with GWD. Similarly, one person indicated he had GWD in 2013, but this was investigated and concluded not to be GWD. The presence of GW-like events is not unusual, particularly in Northern

Ghana. As noted by Eberhard, et al. in 2001 and 2010, *Onchocerca volvulus* has been misreported as GW in the Central African Republic, Uganda, Côte d'Ivoire, Cameroon and Ghana. The CDC confirmed that several cases originally detected as GWD between 2006 and 2010 were in fact O. volvulus (Eberhard, et al., 2010). Nevertheless, these four rumored reports highlight the necessity for the GGWEP to continue to raise awareness of GWD, the reward scheme, and requisite reporting modalities.

The study sample did not allow the comparison of results between the Dagomba and Gonja ethnic groups, two groups heavily affected by GWD in Ghana, as the targeted communities were in Dagomba cultural areas. However, based on the available sample of Gonja respondents, there was no indication they perceived the absence of GWD differently than the Dagomba.

The benefits of the GWEP are widely understood. However, little attention has been given to how local populations perceive the disease. One study in Northern Ghana, amongst the Anufo ethnic group, looked at disease classification in terms of how GW was ranked against other more virulent diseases, though the study did not address how the existence or absence of GW would impact their lives (Bierlich, 1995). As public health programs progress through their lifecycle, they must remain focused on the beneficiaries. This requires following up with beneficiaries after successful, or unsuccessful programs to reinforce the value of the lessons learned during the program.

While this study highlights Ghanaians perceptions about GWD eradication, additional studies should consider evaluating the impact of the indirect benefits, such as safe water and health education, communities received vis-à-vis the GGWEP, in formerly GW endemic areas. The GGWEP, in particular, garnered substantial investment towards the provision of safe water in endemic areas, yet the level of development has been slow and uneven. Public health economists

grappled with determining the economic impact of GWD in the early 1990s, but little has been done to evaluate or analyze those findings based on the case counts that actually occurred in particular countries.

Since the beginning of the GGWEP, the endemic regions of Ghana have not benefitted from significant infrastructural development (Ghana Statistical Service, 2013). Apart from what the GGWEP did to garner support for safe water development from United Nations Children's Fund (UNICEF), United States Agency for International Development (USAID) the European Union (EU), the Conrad Hilton Foundation, and Rotary International, to name a few, direct government investment has been meager. The inability to direct bilateral aid and government investment to improve the standard of living across the country required the investment of millions of dollars to combat GWD and other neglected tropical diseases (NTDs) that might have otherwise been unnecessary. The documentation of an insider's view of what eradication of GWD meant to the people of Ghana may help policymakers and funders uphold the commitments outlined in the London Declaration on Neglected Tropical Diseases (London Declaration on NTDs, 2012).

As the final chapter of the global GW eradication campaign nears, the importance of understanding the perceived value of the absence of the disease among previously affected residents cannot be understated. Thankfully, GW will become a forgotten disease, but the lessons for public health remain profound. Documenting the value of removing a disease or problem, in quantitative and qualitative terms, will help future public health programs plan interventions with new insight into the populations targeted. There is no final public health program and each must learn from those that have come and gone before it, just as the GWEP was born out of the success of the smallpox eradication campaign.

Chapter 5: Journal Article

Title

What it Means to be Guinea worm Free in Ghana: An Insiders Account from Northern Ghana

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Disclaimer

The views expressed in this article are the authors own and do not necessarily reflect the views of the institutions or funders.

Competing Interests

None declared.

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Word Count

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Figures and Tables

Tables 2
Figures 3

Abstract

Objective To provide population-based evidence documenting the value attributed to the eradication of Guinea worm by residents of formerly endemic communities in Ghana.

Methods A retrospective, cross-sectional study in seven villages in Northern Ghana was conducted. Surveys were conducted with 143 individuals and 16 focus groups. The communities were selected because of their recent history of Guinea worm disease and the high historical incidence. Responses were examined through descriptive statistical analyses.

Findings Individual respondents and focus groups highlighted five life characteristics impacted by Guinea worm: health, work, market attendance, school attendance and general mobility. Nearly 100 percent of respondents (542/543) expressed that GWD negatively impacted them, and their lives improved following the eradication of GWD. Those previously infected with Guinea worm were incapacitated an average of six weeks per Guinea worm event.

Conclusion The value residents placed on the absence of Guinea worm highlights both the impact infection had on the pursuit of social and economic advancement and the newfound ability to be healthy and productive again. In January 2015, the World Health Organization, on the recommendation from the International Certification Commission for Dracunculus Eradication, certified Ghana free of Guinea worm disease. While the certification is of great importance to the global campaign to eradicate Guinea worm, it is even more important to the people of Ghana.

Introduction

Dracunculus medinensis, commonly referred to as Guinea Worm (GW), is a nematode parasite that generally only affects human beings (Hopkins & Hopkins, 1991; Muller, 1971). Also known as the *fiery serpent* because of the generalized burning sensation one feels when the worm is about to emerge, GW is referenced in the bible and has been recovered from mummies in Ancient Egypt nearly 3,000 years old (Hopkins & Hopkins, 1991).

Although the global campaign to eradicate Guinea worm disease (GWD) began at the Centers for Disease Control and Prevention (CDC) in 1980, it was not until 1989 that Ghana initiated the Ghana Guinea Worm Eradication Program (GGWEP) and detected 179,556 cases of GWD (Department of Health and Human Services, 1990). This was the second highest recorded incidence of GW only to Nigeria (Department of Health and Human Services, 1990; Edungbola, et al., 1992). In 1989, disease surveillance efforts in Ghana documented a concentrated burden of the disease in the Northern Region, a phenomenon which remained true until the final cases of the campaign (Cairncross, et al., 2012). Nearly all of the socio-economic and health indicators in the region rank between eighth and tenth out of the ten regions and are all lower than the national average (Ghana Statistical Service, 2013). The region also has a relatively small population (1,820,806) spread over a large land area (70,000 KM^2). The people of the Northern Region are primarily subsistence farmers and practice small-scale animal husbandry. The region experienced repeated internal conflict throughout the mid-1990s, including the highly referenced 'Guinea Fowl War', which led to an exodus of health workers and a reduction in the provision of health services, including interventions aimed to eradicate GWD (Cairncross, et al., 2012; Jonsson, 2007; Assefa, 2001). These challenges, together with a long dry season (November to April) and difficulties in extracting ground water, provided suitable conditions for the transmission of GW.

Despite several periods of stagnating GW incidence in the 1990s and early 2000s, Ghana's last reported case of GWD was in May 2010 (Cairncross, Tayeh & Korkor, 2012). Having successfully observed 14 months of zero case reports by July 2011, Ghana celebrated the interruption of Guinea worm transmission (The Carter Center, 2011). Following three years of zero case reports, the GGWEP submitted a comprehensive country report to the International Committee for the Certification of Dracunculiasis Eradication (ICCDE) and the World Health Assembly (WHA) to approve a request to be certified free of GWD. In January 2015, Ghana was granted certification by the WHO (The Carter Center, 2015).

Since the beginning of the GGWEP, the endemic regions of Ghana have not benefitted from significant infrastructural development (Ghana Statistical Service, 2013). Apart from what the GGWEP did to garner support for safe water development from partners including UNICEF, the EU, the Conrad Hilton Foundation, and Rotary International to name a few, direct government investment has been meager. The inability to direct bilateral aid and government investment to improve the standard of living across the country has required the investment of millions of dollars to deal with GWD and other neglected tropical diseases (NTDs) that might have otherwise been unnecessary.

Literature about the culture and people of the Northern Region, including perceptions about western medicine and several studies elaborating the financial impact of GWD in Ghana and Nigeria, exist (Kim, et al., 1997; Bierlich, 1995; Belcher, 1975). Additionally, while a myriad of research has been conducted on GW's molecular structure, lifecycle, and epidemiology since the late 1800s, there is no population-based evidence documenting the value attributed to GWD eradication by residents in endemic communities, either in a pre or post-eradication environment (Fedchenko, 1897; Muller, 1971; Belcher, et al., 1975; Muller, 1979; Hopkins, 1983; Smith, et al., 1989; Watts, et al., 1989; Imtiaz, et al., 1990; Hours & Cairncross, 1994; Kim, et al., 1997). This study was designed to understand the attitudes and perceptions of Ghanaian's following the eradication of GWD.

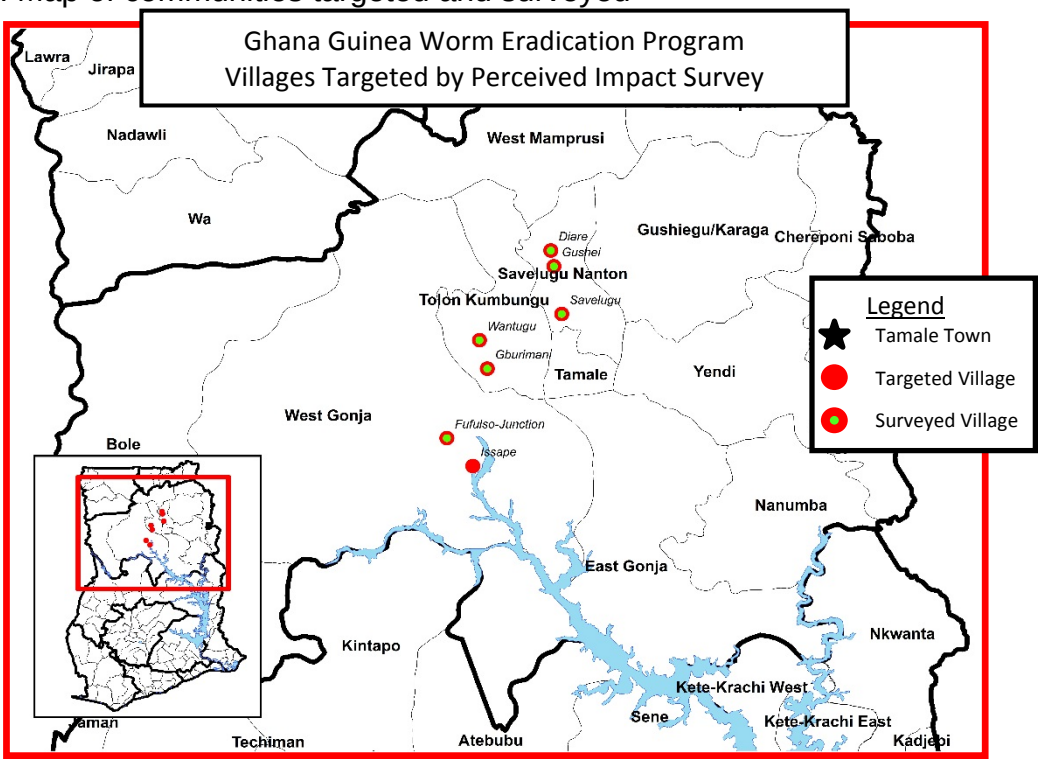
Methods

The study was retrospective and cross-sectional as it detailed perceptions, attitudes and beliefs about the impact of eradication of GWD in Northern Ghana. Due to the dearth of literature about attitudes towards GWD in Northern Ghana, house-to-house surveys and focus group discussions were conducted. Furthermore, the investigators utilized a concurrent strategy design so that the survey tools captured relevant demographic data and detailed direct and indirect experiences with GW simultaneously (Hewson, 2006). Prior to implementation, a pilot test of the survey instrument was conducted within a sub-section of Tamale town. The sample represented the same demographic targeted in the study and the pilot test confirmed the reliability and validity of the survey tools. In addition, the pilot helped to improve the logistical planning required to conduct interviews across the seven villages.

Village Selection

Due to the historically high incidence of GWD in the Northern Region and the unique occurrence of GW in urban settings (not observed in other countries), the study targeted both urban and rural communities to generate an understanding of perceptions in both environments. The urban towns of Saveulgu, Diare and Fufulso Junction were surveyed in addition to the more remote villages of Gburimani, Wantugu, Issape and Gushie. The communities were all in the Northern Region and represented both the Dagomba and Gonja ethnic groups, the two ethnic groups were the most heavily GWD burdened ethnic groups in Ghana (see Figure 1).

Figure 1: Map of communities targeted and surveyed



Source: *GHS/MOH/GGWEP*

The study targeted a minimum of 30 households to interview and five focus group discussions in each of the three towns (Savelugu, Diare and Fufulso Junction). In the four smaller communities (Gburimani, Wantugu, Issape and Gushie) a minimum of 5-20 interviews and 2-3 focus groups were targeted. In the communities where schools were present at least one focus group was targeted in a school setting.

A staff member of the Ghana Health Service provided translation to and from English into Dagbani and Gonja for the interviews. A handheld tablet was used to collect the quantitative data and paper questionnaires were used to record responses to open ended questions. To ensure the accuracy of the transcription, interviews were also recorded and transcribed daily.

Household and Participant Selection

To ensure random selection of household participants, the investigator went to the center of the targeted village, spun a bottle, and proceeded in the direction of the bottle to the first house encountered. In each household the head of household (or representative) was selected to be interviewed, and was read the verbal consent form to ensure the respondent was adequately informed of the nature and substance of the interview. If consent was provided, the investigator further inquired if the interview could be digitally recorded. Upon approval, a private location was identified to ensure privacy and prevent potential bias. After completing the first interview, a second interview was conducted with another member of the same household.

If the head of household never had GWD, the interview was still conducted. However, when the second participant was identified, the investigator attempted to select a member of the household that previously had GWD. If no individual previously had GWD, the investigator attempted to conduct an interview with a household member over 19 years of age. If no one above 19 years was available, the investigator selected a second interviewee 19 years or younger. When possible, the investigator attempted to conduct the household interviews with one male and one female. If only a group of children were present, the investigator conducted a focus group instead of a household interview.

After surveying the household, the investigator spun the bottle again to identify the next household and applied the same household selection process as above. To minimize the clustering of households, the interval between houses was determined based on the size of the village. In smaller villages, the first house in the direction of the bottle was visited, while the second or third house was selected in an urban town. In villages with populations between 500 and 4,000, 5-20 household interviews were conducted (see Table 1), and in larger villages, 4,001-44,000, at least 30 households were selected.

Focus Group Selection

In addition to household interviews, focus group discussions were conducted to ensure that perceptions across demographic groups were obtained. Focus group discussions captured input from the following age groups: 5-18, 19-35, 36+ years of age. If a household was only comprised of children, a focus group survey was conducted. Schools were also targeted for focus group discussions, thus addressing a portion of the 5-18 year cohort not explicitly targeted during the individual household interviews. During discussions the investigator ascribed comments by approximate age and sex of the respondent to simplify the summation of responses.

Table 1: Communities targeted and implemented surveys

Village Name	Population (*2009*)	No. of Households	No. of Household Targeted	No. of Household Surveyed	No. of Focus Groups Targeted	No. of Focus Groups Surveyed
Savelugu	43,234	4,323	30	30	10	3
Diare	13,836	1,383	30	30	7	3
Fufulso-Junction	5,524	552	30	32	5	3
Gburimani	2,525	252	10	21	2	3
Wantugu	4,426	442	20	20	3	2
Gushei	1,270	127	7	10	2	2
Issape	520	52	5	0	2	0
TOTAL	**71,335**	**7,131**	**132**	**143**	**31**	**16**

The investigator met with district health officials and community chiefs as part of the community entry protocols and was consistent in the administration of each question to preserve the integrity of the survey and ensure consistency throughout implementation (Russell, 1988). Permission to conduct and record interviews was obtained from all respondents. According to local regulations, the headmaster provided consent to discuss

GWD, though general consent amongst the students was requested and anyone electing not to participate was not be obligated to do so.

Ethical Issues

Prior to the study's implementation, the project proposal and study tools were submitted to the Emory University Institutional Review Board (IRB) for review. The IRB determined the study did not require review. In addition the Ghana Ministry of Health approved the study as operational research and thus required no further review.

Results

A total of 143 head of household interviews were conducted in six of the seven targeted towns and villages. Issape, in the Central Gonja District, could not be visited due to inaccessibility caused by heavy rains. In addition, 18 focus group discussions were conducted capturing 400 residents across all age-groups, including two schools in Tamale town, capital of the Northern Region.

Of the individual respondents, 74 were male and 69 were female, with generally equitable distribution across the 16-25, 26-50 and 51+ years age groups (see Table 2). Farming and housewifery were the two dominant occupations, representing 70 and 52 percent of the male and female respondents respectively. Although most of the housewives also actively participated in farming activities, only their first response was analyzed as it reflects their primary occupation.

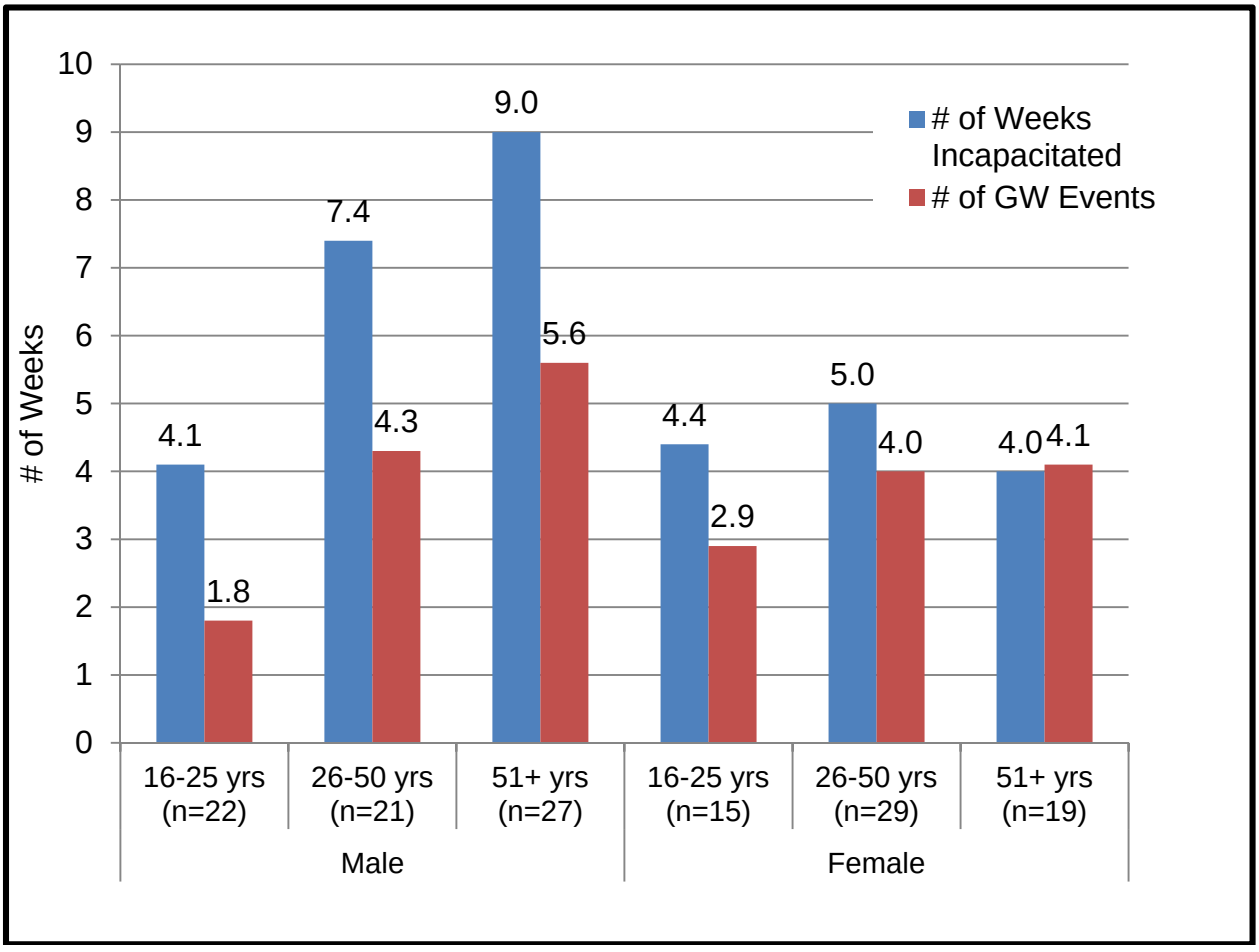
Table 2: Personal experience with GWD of 143 individual respondents

	Number	Number Ever had GWD	Average Years Since Last Infection of GWD (Range)	Average Number of GWs in Lifetime (Range)	Average Number of Times GW Emerged During Lifetime (Range)	Average # of Weeks Incapacitated (Range)
Individual Respondents						
ALL	143	133	11.9 (2-60)	7.3 (1-75)	3.9 (1-30)	5.8 (1-52)
Age Profile						
Male	74	70	13.9 (1-60)	7.2 (1-40)	4 (1-20)	6.5 (1-52)
16-25	22	22	9.1 (2.5-22)	2.9 (1-6)	1.8 (1-3)	4.1 (1-12)
26-50	22	21	12.1 (3-30)	8 (1-35)	4.3 (1-15)	7.4 (0.5-52)
51+	30	27	19.3 (1-60)	9.4 (1-40)	5.6 (1-20)	9 (1-52)
Female	69	63	9.7 (3-45)	7.7 (1-75)	3.9 (1-30)	4.5 (1-20)
16-25	16	15	6.1 (3-10)	6.7 (1-30)	2.9 (1-10)	4.4 (1-12)
26-50	33	29	11.6 (3-40)	7.7 (1-75)	4 (1-30)	5 (2.5-20)
51+	20	19	9.6 (2-45)	7.6 (1-35)	4.1 (1-10)	4 (1-8)

Of the 143 respondents, 133 claimed to have experienced GWD at least once in their lifetime. On average, respondents had nearly four GW events (separate occurrences of

GWD, not multiple worms at one time), and seven worms in their lifetime (see Figure 2). Ninety-seven percent (129/133) of the respondents were incapacitated for an average of six weeks. Several respondents indicated they were incapacitated for an entire year due to complications resulting from secondary infections and having multiple worms emerge throughout the year. Two male respondents reported they were incapacitated for one year due to multiple worms. Females reported fewer worms and shorter periods of incapacitation. All respondents who had GWD reported scarification at the location of worm emergence. Three percent (4/133) of the respondents indicated continued pain associated with the area where the worms emerged and 1.5 percent (2/133) reported persistent difficulty ambulating due to related infections. This is consistent with studies highlighted by Imtiaz, Hopkins and Ruiz (1990).

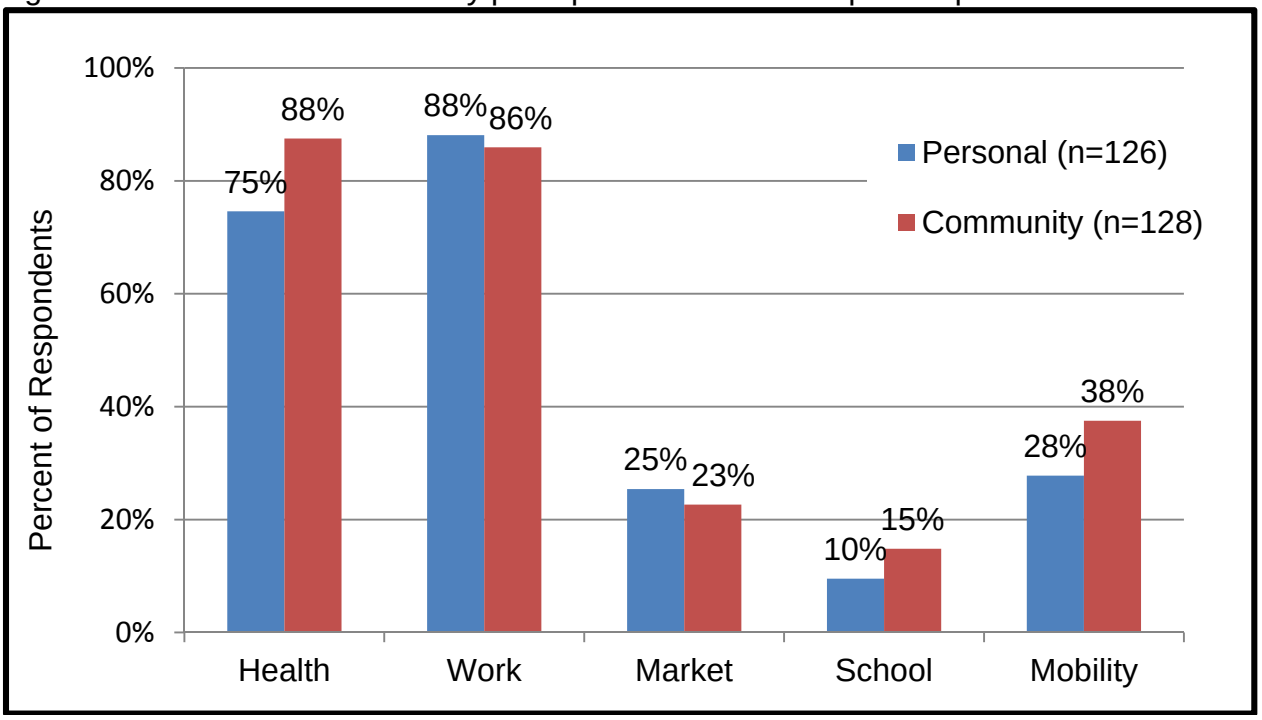
Figure 2: Average number of weeks respondents were incapacitated and the number of GW events they experience in their lifetime



All 143 household respondents indicated that the absence of GW had changed their life, both individually and as a community. Results from open-ended questions about how and in what ways the absence of GW impacted their lives individually revealed that between 75 and 88 percent of respondents believed health and work (i.e. farming, business,

household chores, etc.) improved significantly (see Figure 3). More males cited improved farming first, whereas females indicated improved health. All female respondents that cited improved market and work also mentioned the ability to focus more time and attention to small business and trading activities. Similarly, all the men indicated an increase in productivity from farm labor (and not losing entire harvests). Although health and work were principal areas of improvement, between 10 and 38 percent of respondents also noted improved mobility, market activities and school attendance. Similar themes were acknowledged at the communal level, however, there was a slight increase in health and mobility improvements from a communal perspective compared to the individual perspective. There was no distinguishable difference between Dagomba and Gonja respondents.

Figure 3: Personal and community perception of activities improved post-GW eradication



In addition to individual interviews, 18 focus group discussions were held (including 6 school focus groups), with a total of 400 participants. The primary themes identified by the groups were consistent with those of the individual interviews and included health, work, economics and school performance. More than 90 percent of the focus groups identified work as the primary activity impacted by GWD and referenced the impact as being more significant at the community level. Overall, 99.8 percent of respondents (542/543) expressed that GWD had a negative impact on their lives and that they had experienced improvement in their livelihood post GW eradication.

Limitations

The methodology applied in the study was limited in several ways. Recall bias was a primary limitation, given the average 12-year gap since the most recent experience with

GWD. This potentially skewed the study's findings by over or understating the perceived changes post-GW eradication. The themes addressed by respondents were sincere as they were consistent with the impact and effects associated with a physically incapacitating disease. Respondents provided general accounts of their experience with GW, but there is no baseline data to compare their perceptions prior to the eradication of GW. Ghana's economy has grown significantly over the past decade, which could have also influenced respondents, but much of the responses focused on physical inputs and not on variables influenced by macro-economic conditions.

Discussion

Although the elimination of a public health problem is in itself the definition of success, this study provides an account of how the eradication of GWD was perceived in Ghana. This survey is the first known attempt to collect population-based evidence from a post GW endemic country to document the value attributed to GWD eradication by residents in formerly endemic communities.

The study showed that 97 percent of the respondents were incapacitated and were unable to carry out their normal duties for an average of 6 weeks. This is also consistent with the 6-15 weeks of incapacitation reported in previous studies (Kim, et al., 1997; Watts, et al., 1989; Belcher, et al, 1975). The study also showed that the duration of incapacitation was longer for people over 25 years. This represents the adult working cohort, who by virtue of their responsibilities, drink more unsafe water outside of the household, and are thereby at higher risk for acquiring the disease. Since farming is the main occupation for most of the respondents and infection of the disease is most prevalent during the farming season (May to October), incapacitation had a direct impact on agricultural productivity. Furthermore, as identified by other researchers, children also missed school either because they were incapacitated by the disease or as a consequence of replacing sick relatives in agricultural activities (Karam & Tayeh, 2006). Nearly all respondents specifically mentioned that GWD resulted in lost crop production, a loss of dignity and economic and social hardship not only in the last decade, but as far back as their oral histories could recount.

The study sample did not allow the comparison of results between the Dagomba and Gonja ethnic groups, two groups heavily affected by GWD in Ghana, as the targeted communities were in Dagomba cultural areas. However, based on the available sample of Gonja respondents, there was no indication they perceived the absence of GWD differently than the Dagomba.

The anticipated benefits of a successful GWEP are widely understood. However, little attention has been given to how local populations perceive the disease. One study in Northern Ghana, amongst the Anufo ethnic group looked at disease classification in terms of how GW was ranked against other more virulent diseases (Bierlich, 1995), though the study did not address how the existence or absence of GW would impact their lives. As public health programs proceed through their own lifecycle, the responsibility to remain focused on the beneficiaries does not subside. This requires following up with

beneficiaries even after the supposed success of the program to reinforce the value of the lessons learned during the program.

While this study highlights Ghanaians perceptions about GWD eradication, additional studies should consider evaluating the impact of the indirect benefits, such as safe water and health education communities received vis-à-vis the GGWEP in formerly GW endemic areas. The GGWEP, in particular, was able to garner substantial investment towards the provision of safe water in endemic areas, yet the level of development has been slow and uneven. Public health economists grappled with determining the economic impact of GWD in the early 1990's, but little has been done to evaluate or analyze those findings based on the case counts that have actually occurred in particular countries. The documentation of an insider's view of what eradication of GWD has meant to the people of Ghana may help policymakers and funders uphold the commitments outlined in the London Declaration on Neglected Tropical Diseases (Declaration, 2012).

As the final chapter of the global GW eradication campaign nears, the importance of understanding the perceived value of the absence of the disease among previously affected residents cannot be understated. Thankfully, GW will become a forgotten disease, but the lessons for public health remain profound. Documenting the value of removing a disease or problem, in quantitative and qualitative terms, will help future public health programs plan interventions with new insight into the very population targeted. There is no final public health program and each must learn from those that have come and gone before it, just as the GWEP was born out of the success of the smallpox eradication campaign, so too another is to come after Guinea worm is gone.

Acknowledgements
The authors would like to thank the communities in which the study was carried out. In addition, the involvement of Mr. Emmanuel Aweinko as both translator and liaison with district health authorities facilitated the study's smooth implementation and successful completion. Lastly, much appreciation and thanks is extended to all the village volunteers and former and current GGWEP staff who impacted the lives of Ghanaian's through the eradication of GWD.

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Competing interests:
None declared.

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Appendices

Appendix I: Survey Verbal Consent Script

"Hello, my name is [*investigator's name*]. I am assisting the Ghana Guinea Worm Eradication Program (GGWEP).

I am here to collect information on the perceptions (attitudes/beliefs) towards Guinea worm disease (GWD).

If you agree to an interview the information you share with me will be used to provide feedback to the GGWEP and various stakeholders in the eradication of GWD.

This [*interview, group discussion*] will take about 35 minutes of your time.

There is no risk of a breach of confidentiality. I will not link your name to anything you say, either in the transcript of this [*interview, discussion, etc.*] or in the text of my report or any other publications.

There are no other expected risks of participation.

Participation is voluntary. If you decide not to participate, there will be no consequence. You can, of course, decline to [*discuss any issue, answer any question, etc.*], as well as to stop participating at any time.

If you have any additional questions concerning this research or your participation in it, please feel free to ask me.

I would like to make a tape recording of our discussion, so that I can have an accurate record of the information that you provide to me. I will transcribe that recording by hand, and will keep the transcripts confidential and securely in my possession.

Do you have any questions about this interview? Do you agree to participate and may I record our discussion?

If so, let us begin the questionnaire…"

Appendix II: Household Interview Tool
Ghana Guinea Worm Eradication Program
Impact of Eradication Questionnaire

Region: _____ District: _____ Sub-district: _____
Village: _____ Population: _____ Households: _____
GPS Coordinates: _____ Household Name: _____
Name: _____
Age: _____ Sex: _____ Primary Occupation: _____

1. Have you ever had GWD? (Show GW ID Card)

   Y or N

   If no, ask if any member of the household has ever had GWD. If someone else in the household has had GWD and is present, ask if they can be interviewed separately following this interview.

   If respondent has not personally had GWD, skip to question 7
2. How many times have you had GWD?
3. When was the last time you had GWD?
4. What was your occupation the last time you had GWD (farmer, trader, student, etc.)?
5. How many weeks did you have GWD?
6. Did GWD affect your occupation (work/school)?

   Y or N

   If yes, how and for how long/how many days or weeks?
7. Did GWD affect any other activities in your life or in your community?

   Y or N

   If yes, which activities were affected and in what ways?
8. Has the absence of GWD changed your life?

   Y or N

   If yes, please describe how?

   Individual: How has the absence of GWD changed you/your family?

   Community: How has the absence of GWD changed the community?

9. Have you seen or heard about a case of GWD in the past two years? (Show GW ID Card)

Appendix III: Focus Group Interview Tool

Ghana Guinea Worm Eradication Program
Impact of Eradication Questionnaire

Region: _____ District: _____ Sub-district: _____
Village: _____ GPS Coordinates: _____
Age Group: 5-18, 19-35, 36+ (*circle those applicable*)
Male: % Female: % (*if a very large group, indicate approximate sex distribution*)
# of Participants: _____ *(take a headcount or estimate size as best as possible)*
If a school, indicate primary or secondary level *(circle one)*

1.) What year was the last case of GWD in your community?

2.) How did GWD affect your community?

3.) What activities did GWD affect in your life?

4.) What has the absence of GWD meant to your community?

Individual:

Community:

Appendix IV: IRB Letter

EMORY UNIVERSITY | Institutional Review Board

August 8, 2013

Adam J. Weiss
Assistant Director, Dracunculiasis Eradication
The Carter Center

RE: Determination: No IRB Review Required
Title: *Survey Protocol to Assess the Perceived Impact of Guinea Worm Eradication in Ghana*

Dear Mr. Weiss:

Thank you for requesting a determination from our office about the above-referenced project. Based on our review of the materials you provided, we have determined that it does not require IRB review because it does not meet the definition of "research" with human subjects as set forth in Emory policies and procedures and federal rules, if applicable. Specifically, in this project, you will conduct house-to-house surveys and focus group discussions to detail perceptions, attitudes, and beliefs about the impact of the eradication of Guinea Worm Disease in Ghana. These procedures are intended to identify and document the legacy of Guinea worm eradication as perceived by residents in formerly endemic communities. This documentation will be integrated into Ghana's Guinea Worm Eradication Program's impending country report to the International Committee for the Certification of Dracunculiasis Eradication and World Health Assembly in their request that Ghana be certified free of Guinea Worm Disease.

Please note that this determination does not mean that you cannot publish the results. If you have questions about this issue, please contact me.

This determination could be affected by substantive changes in the study design, subject populations, or identifiability of data. If the project changes in any substantive way, please contact our office for clarification.

Thank you for consulting the IRB.

Sincerely,

Carol Corkran

Carol Corkran, MPH, CIP
Interim Team Lead

Emory University
1599 Clifton Road, 5th Floor - Atlanta, Georgia 30322
Tel: 404.712.0720 - Fax: 404.727.1358 - Email: irb@emory.edu - Web: http://www.irb.emory.edu
An equal opportunity, affirmative action university

Appendix V: Letter of Invitation

In case of reply the number and the date of this letter should be quoted.

GHANA HEALTH SERVICE
PRIVATE MAIL BAG
MINISTRIES
ACCRA.
GHANA.

My Ref. No. GHS/MOH/PHD/GWEP/51

TEL. 0302-662014

Your Ref. No. .....

August 15th, 2013

The Ambassador
Ghana Embassy
USA

RE: GHANA VISA APPLICATION FOR TORBEN VESTERGAARD-FRANDSEN

The Ghana Guinea Worm Eradication Program is inviting Mr. Torben Vestergaard-Frandsen, a key partner to the global eradication of Guinea worm disease, to assist with an attitudes and behavior study about the legacy of the Guinea Worm Eradication Program in Ghana during September and October 2013. The Ghana Health Service has given approval to the project and Mr. Vestergaard-Frandsen will be working with the under listed staff during his visit.

Mr. David Agyemang
Deputy National Program Manager
Ghana Guinea Worm Eradication Program
Ghana Health Service
E-mail: dkagyemang4@gmail.com
Phone: 233 3021 684271 / 233 3021 684310

Should you require any additional information, please do not hesitate to contact the Ghana Health Service Guinea Worm Programme on 0244643142at any time.

Thank you in advance for your assistance.

Sincerely,

Dr Erasmus E.A. Agongo
Ag. Director-General

Cc:
Director of Public Health
Programme Manager, GWEP