Action Through Enterprise

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Tackling Causes of Disability: Iodine Deficiency Report

Goitre Screening Study in Lawra District – November 2015

By Leela Shanti
for ATE in partnership with Ghana Health Service
Action Through Enterprise (ATE)
Registered Charity Number: 1149988
Fighting poverty in Lawra, Upper West Ghana
www.ateghana.org

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About the Author

Leela Shanti has a Masters in Development from the University of London and first came to Ghana as a Voluntary Service Overseas (VSO) Community Advocacy Support Officer in 2012. She has worked in equality in higher education and the health sector in the UK, and on national participation projects with an organisation supporting families with disabled children across England. She has worked on two DfID- and Comic Relief-funded education projects in Ghana and has been volunteering with Action Through Enterprise (ATE) since June 2015.

Abbreviations

ATE	Action Through Enterprise
CHO	Community Health Officer
CHPS	Community Health Programme Service
DHA	District Health Assembly
DHMT	District Health Management Team
FAO	Farming and Agriculture Organisation of the United Nations
GAIN	Global Alliance for Improved Nutrition
GHS	Ghana Health Service
GIMPA	Ghana Institute of Management and Public Administration
GSS	Ghana Statistics Service
IDD	Iodine Deficiency Disorder
IGN	Iodine Global Network (formerly ICCIDD)
MDG	Millennium Development Goal
MoFA	Ministry of Food and Agriculture
NGO	Non-Governmental Oranisation
NNP	National Nutrition Plan
SNAP	Special Needs Awareness Programme
SUN	Scale Up Nutrition
UNDP	United Nations Development Programme
UNICEF	United Nations Children's Fund
USI	Universal Salt Iodization initiative
WFP	World Food Programme
WHA	World Health Assembly
WIFA	Women in Fertile Age
WHO	World Health Organisation

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Executive Summary

Iodine deficiency disorders (IDD) are one of the most pervasive causes of cognitive impairment which can start even before birth (World Health Organisation). In Ghana, it is estimated that about 120,000 children born each year are at risk of developing intellectual impairment as a result of iodine deficiency whilst in the womb. Approximately 13% of these babies are severely impaired with congential disorders such as cretinism. This has profound costs and consequences for their futures, for their families and ultimately their communities.

The World Health Organisation (WHO) states that women of reproductive age, particularly pregnant and lactating women, are most susceptible to iodine deficiencies which places their babies at high risk of irreversible mental impairment. Therefore, the right levels of iodine in women's diets are vital both for their own health and for the healthy development of their babies. The easiest, cheapest and most effective way to ensure iodine is in the diet in order to prevent and control IDD is through regular use of adequately iodised salt. However, despite concerted efforts of the Government of Ghana and leading non-governmental organizations, average household consumption of adequately iodised salt has remained at 35%, which is well below the national target of 90% set by the government a decade ago (WHO, UNICEF).

Action Through Enterprise (ATE) work to tackle poverty and support families with children with disabilities in Lawra District, Upper West, Ghana; a predominantly rural district with a 100% poverty incidence (UNDP) and food insecurity through 5 months of the year (Ministry of Food and Agriculture). Working in partnership with the Ghana Health Service, ATE set out to find out the prevalence of iodine deficiency amongst women in fertile age as a known cause of risk to children being born with disabilities and developmental delay. As iodine deficiency is the primary cause of goitre, an enlargement of the thyroid gland, this study was carried out by screening consenting participants for goitre by means of observation and palpation. Screening was undertaken in 7 Community Health Service Programme (CHPS) Zones comprised of 26 communities (made up of about half of the total district population) through 3 weeks in September 2015.

Our findings show a goitre prevalence of 5.3% amongst women in fertile age across Lawra District. This represents 44 out of 832, or more simply put, 1 in 20 women in fertile age who have suspected goitres[1]. The CHPS Zone with the highest prevalence of goitre was Boo CHPS Zone (9.4%), located to the east of the district, bordering Jirapa District. In addition, 1.2% of the women screened had painful thyroid glands, which may or may not be due to iodine deficiency and have therefore been referred for further diagnosis. We also found that 40 children born to participants in this study have disabilities, and 22% of these disabilities could be attributable to iodine deficiency whilst developing in the womb.

These findings suggest that iodine deficiency in the district is at a level which could be considered a public health problem (over 5%) which poses high risks to children being born with severe disabilities. This requires investment in interventions to increase iodine supply and consumption. In particular, steps must be taken to ensure that women regularly consume iodised salt during pregnancy and whilst breast-feeding so that their babies can develop normally. Without intervention, iodine deficiency will surely continue with social and economic costs for women, children and communities in Lawra District as a whole.

[1] This report refers to goitres as 'suspected goitres' until such time as the findings of the goitre screenings are followed up and confirmed or amended by a clinician appointed by the Ghana Health Service.

Introduction

ATE & the purpose of the goitre screening study

Action Through Enterprise (ATE) is a registered charitable organisation which has been working to reduce poverty in Lawra District, Upper West Region, since 2012. There are three key areas of work that we do to support social and economic development; 1) Education - free school meals and resources to Karbo Primary School and Karbo Junior High School, 2) Enterprise - start-up grants and on-going advice and training to small business owners, and 3) a Special Needs Awareness Program (SNAP) - to improve the lives of families of children with disabilities.

It is through our Special Needs Awareness Programme that we became aware of children with multiple disabilities characteristic of cretinism caused by hypothyroidism during pregnancy; an iodine deficiency disorder (IDD) caused by a lack of iodine in the diet. To investigate the extent of this cause of disabilities in Lawra District, we carried out a study to screen for goitre (enlargement of the thyroid gland), the most visible and easily detectable symptom of iodine deficiency, amongst women of child-bearing age (15-40 years old).

This study was approved and supported by the Regional Health Director, the District Health Director and the District Health Management Team and follows on the heels of a study into usage of adequately iodised salt carried out by the Ghana Health Service (GHS) across the Upper West Region in 2014. We worked in partnership with the Ghana Health Service through their local Community Health Programs Service (CHPS) and Community Health Officers.

Our aim is that the information gained through this study will drive action to reduce iodine deficiency amongst local communities, particularly women of child-bearing age, and therefore reduce the associated risks of children being born with disability and developmental delay.

Background

The importance of iodine

According to the World Health Organisation (WHO), iodine deficiency is the most common, yet easily preventable cause of brain damage in the world [1]. It can cause hypothyroidism and goitre. It is also one of the most pervasive causes of impaired cognitive development in children which can start even before birth (WHO). Iodine is an essential dietary nutrient for the thyroid hormones that regulate growth and development [2]. This is why it is so important during the first 1000 days of life, from pregnancy through infancy, when the damage caused by inadequate iodine intake can be severe and irreversible [3]. Without sufficient intake of iodine for fetuses, infants and children, there are costs to their health, their ability to focus in school and to develop to their full potential. This has profound consequences for their future and the future of their communities (UNICEF).

In Ghana, it is estimated that about 120,000 children born each year are at risk of developing intellectual impairment as a result of iodine deficiency. Approximately 15,600 accounting for 13% of these babies are severely impaired and are unable to develop properly, which has been quantified as resulting in an average of 22 million dollars loss in productivity each year in Ghana [4].

WHO states that the most susceptible group for iodine deficiency disorder are women of reproductive age, particularly pregnant and lactating women, whose babies, if iodine deficient in the womb and when breast feeding, are at high risk of irreversible mental impairment [5]. Adequate levels of iodine in women's diets are vital both for their own health and fertility and for the healthy development of their babies. Iodine deficiency during pregnancy can result in miscarriage, stillbirth, infant mortality, short stature, and congenital abnormalities such as cretinism, a form of mental retardation seen amongst some of the children who attend the ATE Special Needs Awareness (SNAP) group each month. This devastating deficiency is described by WHO as

'spectacularly easily, cheaply and effectively prevented with the use of iodized salt' [1]. The cost of salt iodization per year is estimated at just US$ 0.02‑0.05 per individual covered [5]. Yet Ghana has persistently low iodized salt consumption (UNICEF, IGN) [6].

Spectrum of Iodine Deficiency Disorders (WHO)	
Fetus	Abortions, Stillbirths, Congenital abnormalities, Increased perinatal mortality, Increased infant mortality, Neurological cretinism (mental deficiency, deaf mutism, spastic Diplegia squint), Myxoedematous cretinism (mental deficiency, dwarfism, hypothyroidism), Psychomotor defects
Neonate	Neonatal hypothyroidism
Child & Adolescent	Retarded mental and physical development
All ages (inc. adult)	Goitre, Hypothyroidism, Impaired mental function

Recommended Dietary Allowance (RDA) of iodine
As iodine cannot be stored in the body for long periods, tiny amounts are needed on a regular basis. Several international groups such as IGN, WHO and UNICEF make similar recommendations for daily amounts of iodine intake (in micrograms/day) as follows: Age 0-5 years: 90 mcg | Age 6-12: 120 mcg | Older than 12: 150 mcg | Pregnant and lactating women: 250 mcg [2]

Universal Salt Iodization and factors influencing use of iodized salt in Ghana
Since the World Health Assembly recognized the importance of preventing iodine deficiency in the early 1990s, WHO and UNICEF have recommended universal salt iodization (USI) as the main strategy to eliminate IDD. USI is currently implemented in 120 countries world-wide and many have now eliminated or reduced IDD through salt iodization. This represents a great achievement in international public health (WHO, IGN). Nevertheless, hundreds of millions of people are still at risk (see Global Alliance for Improved Nutrition). Approximately one third of the world's population lives in areas where natural sources of iodine are low, and therefore require the presence of permanent iodine-supplying interventions [5].

Ghana is one of the largest producers of salt in the West African region yet access to and use of adequately iodized salt is not widespread. The Government of Ghana has a USI program which has so far failed to reach the national household iodized consumption target which it set at 90% in 2005. Despite concerted effort from the government and non-governmental sector, adequate consumption, as at 2011, had remained at 35% [7].

A major challenge is that iodine is an unstable substance easily lost from salt, affected by moisture, sunlight, heat and humidity, impurities in the salt and form of iodine present (iodate is most stable)[8]. The way in which salt is produced, packaged, stored, distributed and sold in Ghana's tropical climate affects the amount of iodine present and then lost by the time it is bought in the market and consumed[2].

Some studies on the use of adequately iodized salt in Ghana point to factors leading to high cost and low availability affecting consumers choices, such as high numbers of small-scale salt producers for whom iodization is neither practical nor cost-effective, unabated by weak law enforcement [6, 10, 11]. Another reason cited for low usage of iodized salt is a lack of knowledge and public education on the nutritional value of regularly consuming iodized salt, further determined by levels of poverty and access to information [10].

What is being done to tackle iodine deficiency in Ghana?
Having identified Ghana as one of the top 13 countries at risk of iodine deficiency, UNICEF and GAIN started a USI Partnership Project in 2009 to scale up more efficient models of salt iodization and build sustainable

[2] A market survey conducted in the Western Region in 2010 revealed that 58% of salt sold in markets was iodized, but below the mandated iodization levels (GNA) [9].

markets. GAIN have recorded success in improved supply chains ensuring 5.8 million Ghanaians have access to iodized salt each month [12]. As this represents less than one quarter of the total population (GSS 2014), there is still work to do to ensure iodized salt reaches more people, especially in the most susceptible areas. It is worth noting that UNICEF supported a Health Service-led radio campaign in Bolgatanga, Upper East Region, to educate consumers on the use of adequately iodized salt which successfully raised usage from 24% to 63% in tested households over two years (2009-2011) [6].

In 2011, Ghana joined the Scaling Up Nutrition (SUN) Movement, tackling nutrition and IDD as direct contributing factors to many of the Millennium Development Goals [13]. Currently, Ghana's Cross-Sectoral Planning Group (CSPG), with the support of UN agencies, is in the process of translating its first multi-sectoral National Nutrition Policy (NNP) into a national nutrition scale up plan with importance placed on engaging regional and district level players in Ghana's three Northern regions [14].

Context of poverty, nutrition and maternal health in Lawra District

Lawra District is one of the eleven districts that make up the Upper West Region of Ghana. It lies in the north western corner of the Upper West Region, bounded to the north by Nandom District, to the east and south by Jirapa District and to the west it borders the Republic of Burkina Faso. Following the split from Nandom in 2012, the total area of Lawra District is estimated to be 527.37 kilometers square (GSS, 2012). Current data from Lawra's District Health Management Team as at September 2015 puts the registered population size at 26,499, though the population of the district according to the 2010 Population & Household Census is 54,889 (GSS) [15].

In 2010, the United Nations Development Programme (UNDP) estimated a high incidence of poverty in the district with an estimated daily per capita income of $0.87[3]. According to the 2010 Population and Housing Census the adult literacy rate in Lawra District is 19%; well below national (72%) and regional averages (40%). 83% of the working population in Lawra District are engaged in subsistence farming (UNDP), though food production is low due to the use of traditional farming methods, exacerbated by climatic change, lack of irrigation and declining soil fertility. The Ministry of Food and Agriculture state that people in the Upper West Region experience 5 months of food insecurity a year [16], whilst UNDP confirm that people in Lawra District experience chronic food shortage through April to June when many households can only afford one meal a day [17]. Households who are food insecure subsist on a poor diet of mainly maize and millet, few vegetables, with meat or fish consumed less than once a week, which can have a major impact on their nutritional status [18].

Note on diet: Iodine is found in seafood, such as fish, shellfish, seaweed, plant foods, such as cereals and grains, and cows milk. Diets in most places are low in iodine unless fortified foods or foods from the sea are commonly eaten. The iodine level of food is related to the level of iodine in the soil in which it is produced. Where iodine deficiency exists, goitrogens (toxins that reduce iodine uptake by the thyroid gland) present in 'bitter' cassava, millet and cabbage actually make it worse.

National statistics on nutritional status mask massive regional variations. According to the World Food Programme, the Northern, Upper East and Upper West Regions have some of the highest rates of malnutrition in the country, where four out of ten children under the age of five are stunted or chronically malnourished [19, 20]. Dr Abdulai Adams Forgor, Upper West Regional Director of Health Services, has said that immediate determinants of under nutrition were inadequate food intake and disease or infections related to poor hygiene and sanitation practices [21].

In terms of health infrastructure, Lawra District has one hospital, 4 health centres, a nutrition centre, and 11 functioning Community Health Programme Service (CHPS) compounds (DHMT 2015). Findings from the Ghana

[3] As compared to the National poverty incidence of 28% and Upper West Region incidence of 88% in 2005/06, see UNDP 2010, p.20

Institute of Management and Public Administration Household Survey 2008 suggest that pre-natal and post-natal care are not sought regularly enough to be preventative measures and access to health facilities could pose a danger to child and maternal health [17]. Significant efforts have been made since to provide more health infrastructure [22], however, under-nutrition rates across the region remain worryingly high (Ghana News Agency).

The Study

Objective and Scope

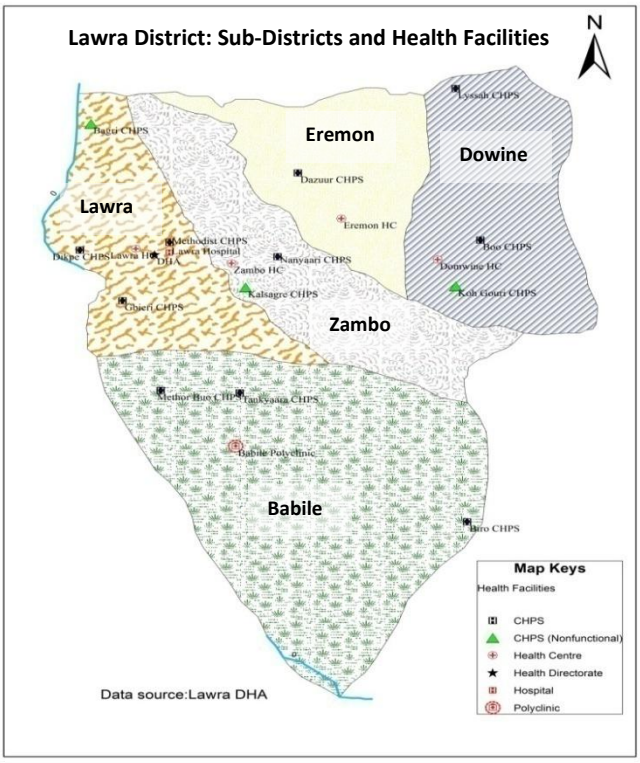
The aim of the study was to collect and analyse data to investigate the scale of IDD amongst women in fertile age (WIFA) by screening between 500 to 1,000 women for goitre across Lawra District. This represents 4%-8% of the total district population of WIFA according to Ghana Statistics Service population figures, or 8%-16% according to current data available from the District Health Management Team.

No. of women in fertile age we aimed to screen	% of WIFA we aimed to screen (based on GSS pop. figures)	% of WIFA we aimed to screen (based on DHMT pop. figures)
500-1,000	**4%-8%**	**8%-16%**

Target participants for this study were women of 15 to 40 years old. We did not include boys, men, girls under 15 or elderly, infertile women because the driving issue was the extent of IDD during pregnancy, known to be a cause of children being born with disability. However, the study may provide some understanding of the level of IDD in the district more broadly and resulting actions may benefit the population as a whole.

In terms of population zones for screening, Lawra District is divided into 5 administrative sub districts, further divided by the District Health Assembly into 18 Community Health Programme Service (CHPS) zones in which a CHPS compound serves local communities with basic primary healthcare. There are 11 functioning CHPS zones in the district. In partnership with the District Health Management Team, we selected one to two functioning CHPS zones from each sub district and prioritized those with the highest population sizes. In total we covered 7 CHPS zones, comprised of 26 communities across the district.

Lawra District Healthcare Sub-Districts and Zones	
Sub Districts	**CHPS Zones** (X = not functioning)
Babile	Tanchara
	Biro
	Cha (X)
Dowine	Boo
	Lyssah
	Koh/Gouri
	Baazing (X)
Eremon	Dazuuri
	Yagra (X)
	Naburnye (X)
Lawra	Gbier
	Dikpe
	Kunyukuo
	Bagri
	Tongoh/Zagkpee (X)
Zambo	Nanyaare
	Kalsagri
	Kokori (X)



Consent and handling of data

Ethics of the study were considered in consultation with the Regional Health Director and in consulting online Ghana Health Service documentation. A written consent form was developed by ATE and approved by the District Health Director, Dr Sandaare (see appendix to this report). It was read to the participants in the local language, Dagari, signed or thumb-printed by the participant and by the person gaining consent before the goitre examination took place. If the participant was under 18 years of age, consent was provided by an older relative or leader of the community. A copy was given to the participant for reference and a record of written consent was kept by ATE. Records are held by the ATE Ghana Programme Manager and ATE Operations Officer. If a suspected goitre or painful thyroid was detected, the participant was asked for permission to be contacted to attend a follow up appointment with a GHS-appointed clinician for further diagnosis. The names of those who have been referred for follow-up diagnosis will be shared with the GHS, principally the DHMT and CHOs, in order to coordinate appointments for the benefit of the women and to verify findings. People photographed gave verbal consent to being photographed for documenting and reporting purposes.

Community entry

In preparation for the goitre screening, the District Health Director sent a letter to all Community Health Officers (CHO) in the selected CHPS zones calling for their cooperation in the study and to guide ATE in the community entry process. Community entry was crucial for ATE to fully brief the community leaders and answer any questions, gain their consent and their support to screen in their communities, and to call on women of child-bearing age to participate. Community entry meetings were attended by the CHO and their Community Health Volunteers, Community Health Chairmen, Chiefs, Sub-Chiefs, sometimes Youth Leaders, Assemblymen, and Queen Mothers also attended. The screening was welcomed and very well received. Announcements promoting the screening were also broadcast on local radio; West Link Radio 88.1.

Community entry at Dazuuri CHPS Compound

Community entry at Dikpe Chief's Palace

The screening process and follow-up

The goitre screening was carried out at seven CHPS compounds, two weighing centres and one health centre by ATE representatives, in partnership with Community Health Officers, supported by Community Health Volunteers and/or Community Health Chairmen.

The screening process consisted of five steps: 1) briefing women gathered for screening, 2) gaining their written consent to participate (or a responsible adult's if under 18), 3) taking some personal details and ascertaining whether they have had any children with disabilities which may be attributable to IDD, 4) the examination - carried out by a trained health professional, either a trained nurse volunteering with ATE or by the relevant CHO, through observation and by palpating the participant's neck, 5) recording if a suspected goitre was

detected and if so, asking whether the participant would be happy to be contacted to attend a follow up appointment with a GHS-appointed clinician for further diagnosis.

The final stage of the study will be the clinical diagnosis carried out by a GHS-appointed clinician of the women referred with suspected goitres. The follow-up to diagnosis will be delivery of any the medical care identified by the clinician. The follow-up to this study will be reporting the initial findings to the District Health Management Team, District Health Director, and collectively discussing potential actions and interventions.

Weaknesses in method of indicating iodine deficiency

ATE accepts that palpation of the neck is not the most sensitive method of detecting a goitre, as compared to ultrasound, but for our purposes was both cost effective and practical. WHO flag that measuring thyroid size, either by palpation or ultrasound, has a limited role in indicating levels of iodine deficiency because it reflects only *chronic* rather than immediate iodine deficiency (urinary iodine excretion, urinary iodine concentration or measurement of dried blood spot thyroglobulin are more effective indicators). In addition, there may be other reasons why a thyroid may be enlarged, which gives further impetus to ensure that the women referred to the GHS gain follow-up appointments, diagnosis and relevant medical attention.

Screening process in pictures

Briefing women at Faalu Weighing Station

Gaining written consent to examine for goiter

Recording participant's personal details

Examination for goiter (observation and palpation)

Percentage of Women in Fertile Age screened

Through the screening process we screened a total of 863 participating women for goitre. 31 women were eliminated from the findings of the study as they were either below 15, estimated to be more than a few years over 40 and no longer fertile, or were from CHPS zones outside of those selected for this study. Therefore the total number of women in fertile age screened on which we base our findings is 832.

Note: Determining the age of women participating was challenging as many people in the area do not know their date of birth. Ages according to identification cards (National Health insurance and voting registration cards) were often inaccurate. If women were near the upper end of the age bracket, they were asked if they were still fertile as an indication of whether to include them in the study. If they were estimated to be much over 40 and no longer fertile, but clearly had a goitre, we recorded their details in order to refer them to a clinician for follow-up diagnosis but separated their data from the study's findings of WIFA screened.

The total population of women in fertile age (WIFA) is estimated by Ghana Health Service at 23.7% of the projected population size for 2015. Based on the population figures provided by the District Health Management Team, the estimated WIFA population for the whole district is 6,280. Having screened 832 WIFA, on average, we screened almost a quarter (22.6%) of the total WIFA from the 7 selected CHPS zones for this study, or 13.2% of the total WIFA for the whole district (DHMT). We have used the DHMT data through this study rather than the Ghana Statistics Service data from 2010, as the DMHT provided a breakdown by CHPS Zone and community.

We screened the highest number of WIFA in Boo (n.220), which has the largest overall population size. The greatest level of participation was in Dazuuri (26.7%) then Boo (25.8%) which have the fewest communities within their zones. The lowest level of participation was in Kalsagri (17.3%), followed by Dikpe (18.7%).

Location		**Women screened**					
Sub District	**CHPS Zone**	**Total no. of participants screened**	**No. of participants eliminated from study**		**No. of WIFA screened** (within scope of study)	**Total WIFA Population***	**% of WIFA screened**
			Under / Overage	From other CHPS Zones			
Zambo	Kalsagri	72	3	0	69	405	17.3%
	Nanyaare	136	4	0	132	552	23.9%
Dowine	Boo	228	1	7	220	854	25.8%
Babile	Tanchara	142	7	4	131	612	21.4%
Lawra	Dikpe	78	1	0	77	412	18.7%
	Gbier	99	3	0	96	452	21.2%
Eremon	Dazuuri	108	0	1	107	401	26.7%
TOTAL:		**863**	**19**	**12**	**832**	**3688**	**22.6%**

*Ghana Health Service estimate the WIFA population to be 23.7% of total population figures, which has been applied to 2015 projected population figures provided by Lawra District Health Management Team.

Findings

Summary of findings by CHPS Zone

The findings of our goitre screening show that out of 832 women in fertile age (WIFA) screened, 44 have suspected goitres[4]. This puts the overall prevalence of goitre amongst WIFA participating in the study at 5.3%. We also recorded that 10 participants (1.2% of WIFA screened) were experiencing painful thyroid glands which may be a further indication of IDD, and will be referred to a clinician for diagnosis.

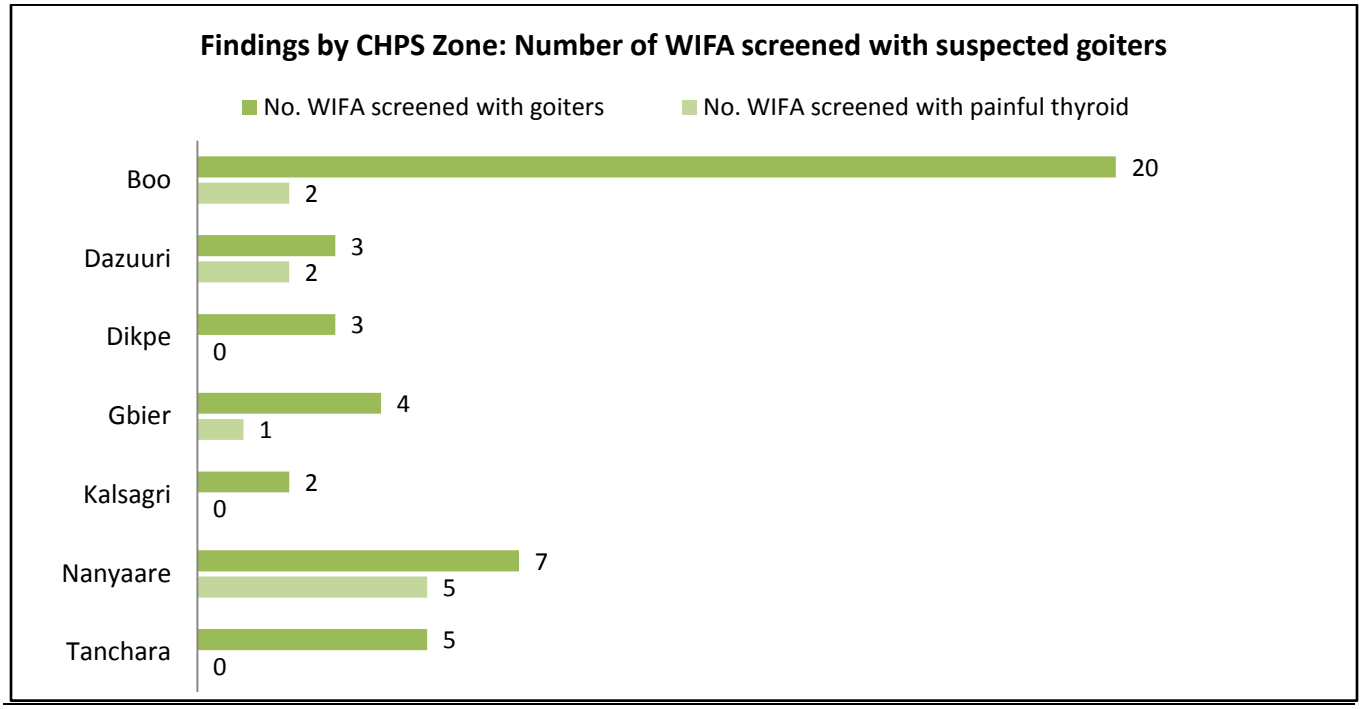
[4] This report refers to goitres as 'suspected goitres' until such time as the findings of the goitre screenings are verified by a clinician appointed by the Ghana Health Service.

Looking at the findings by CHPS Zone, Boo was the CHPS Zone with the highest number of suspected goitres detected, with 20 participants affected – almost as many as the rest of the CHPS zones included in this study put together. This could be expected as this is the CHPS zone where we screened the highest number of women, however, it is also shown to be the CHPS zone with the highest goitre prevalence rate at 9.4%. Nanyare CHPS Zone has the second highest number of suspected goitres detected with 7 participants affected and the second highest prevalence rate of 5.3%. Nanyare also has the highest number of WIFA with painful thyroid (n.5). Dazuuri, Dikpe and Tanchara CHPS Zones had the lowest number of participants with suspected goitres detected (n.3, 3, 2) and Dazuuri CHPS Zone and Kalsagri CHPS Zone had lowest prevalence rates at 2.8% and 2.9% respectively.

Sub District	CHPS Zone	Total no. of WIFA screened	No. of WIFA screened with suspected goitres	Prevalence of goitre amongst the WIFA screened (%)	No. Of WIFA screened with painful thyroid	No. of overage women with goitres
Domwine	Boo	220	20	9.4%	0	2
Eremon	Dazuuri	107	3	2.8%	2	1
Lawra	Dikpe	77	3	3.9%	2	0
	Gbier	96	4	4.2%	0	0
Zambo	Kalsagri	69	2	2.9%	1	0
	Nanyaare	132	7	5.3%	5	3
Babile	Tanchara	131	5	3.8%	0	2
	Total:	**832**	**44**	**5.3%**	**10**	**8**

In total, through the goitre screening, 8 overage women attended screening sessions whom clearly had a goitre, in some cases extremely large and visible. Their data has been excluded from the prevalence rates but their details have been recorded in order to refer them to the clinician. The CHPS Zone with the highest number of overage women with goitres was Nanyare CHPS Zone (n.3). The overage women with goitre bring the total number of women referred to a clinician for further diagnosis to 62; 44 WIFA with goitre detected, 10 WIFA with painful thyroid and 8 overage women with goitre detected.

Examples of some of the more visible goitres detected through the screening process



Summary of findings by Community

Out of 26 communities included in the goitre screening study, within the 7 selected CHPS zones, suspected goitres were discovered in 13 communities (in 16 communities if we consider overage women, see table below). The numbers of suspected goitre detected in the majority of communities were between 0-5. However, the prevalence rate of goitre by community varies quite widely. The communities with the most WIFA with suspected goitres detected were Boo Kal (n.13) and Boo Naayire (n.7). Boo Naayire and Boo Kal had the second and fifth highest prevalence of suspected goitre respectively. Susu community in Tanchara had the highest prevalence of suspected goitre at 20%, though the sample size of WIFA screened from this community was very small (n.15) so may not be representative of iodine deficiency in the community as a whole. Zukpiire community in Kalsagri CHPS Zone had the third highest prevalence of goitre (10%), but again this was from only a small sample of participants (n.10). Nanyaare community had the third highest number of suspected goitre (n.4) and the fourth highest prevalence (9.1%). Tampie community in Nanyaare CHPS Zone had the most WIFA with painful thyroid (n.3).

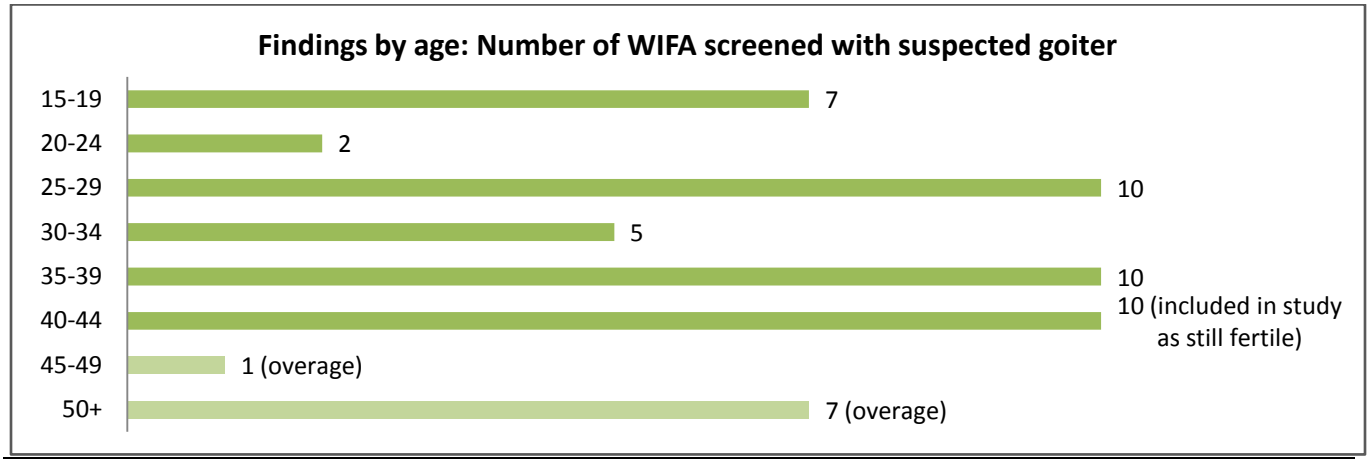
Findings by community (in order of highest to lowest number of goitres detected)						
Community	**CHPS Zone**	**Total WIFA screened**	**No. WIFA with goitres**	**Prevalence of goitre (%)**	**No. WIFA with painful thyroid**	**Overage women with goitres**
Boo Kal	Boo CHPS	156	13	8.3	1	1
Boo Naayire	Boo CHPS	64	7	10.9	1	0
Nanyaare	Nanyaare CHPS	44	4	9.1	2	2
Susu	Tanchara CHPS	15	3	20.0	0	0
Tampie	Nanyaare CHPS	53	3	5.7	3	0
Yikpee	Dikpe CHPS	54	3	5.6	0	0
Dazuuri	Dazuuri CHPS	107	3	2.8	2	0
Tugbule	Gbier CHPS	36	2	5.6	0	0

Gbier Naayire	Gbier CHPS	37	2	5.4	1	0
Koro	Tanchara CHPS	33	1	3.0	0	1
Kalsagri	Kalsagri CHPS	37	1	2.7	0	1
Zupiire	Kalsagri CHPS	10	1	10.0	0	0
Tanchara	Tanchara CHPS	57	1	1.8	0	0
Kondopie	Kalsagri CHPS	6	0	0	0	1
Gbengbee	Nanyaare CHPS	35	0	0	0	1
Ko	Tanchara CHPS	19	0	0	0	1
Pavuu	Kalsagri CHPS	5	0	0	0	0
Faalu	Kalsagri CHPS	11	0	0	0	0
Gbelingka	Tanchara CHPS	7	0	0	0	0
Dikpe	Dikpe CHPS	12	0	0	0	0
Sampasa	Dikpe CHPS	7	0	0	0	0
Ambur	Dikpe CHPS	1	0	0	0	0
Gonper	Dikpe CHPS	2	0	0	0	0
Gongpare	Dikpe CHPS	1	0	0	0	0
Dewog	Gbier CHPS	22	0	0	0	0
Kakaari	Gbier CHPS	1	0	0	0	0
	TOTALS:	**832**	**44**	**5.3**	**10**	**8**

Summary of findings by age group

Looking at the findings by age group in 5-year intervals the detection of goitres is quite broadly spread across all age brackets with 10 suspected goitres detected amongst each of the 25-29, 35-39 and 40-44 age groups, and 7 suspected goitres detected amongst the 15-19 age bracket. There were also 8 goitres found amongst overage women; 7 in the over 50s and 1 in the 45-49 age group. There were a lower number of suspected goitres found in the 20-24 and the 30-34 age brackets, though it is difficult to extrapolate this as a trend as the numbers are small and date of birth of participants is often unknown and therefore inaccurate. One factor to consider alongside age may be residential patterns. It is possible, in this patrilineal community, that some participants may have only recently migrated to the area to live in their husband's family compound and previously accessed different levels of nutrition [23].

In terms of the age groups of WIFA with painful thyroid, the majority (n.3) were in the 35-39 age bracket, followed by 2 in both the 25-29 and 15-19 age brackets, and 1 in each of the 45-49 and 20-24 age brackets.

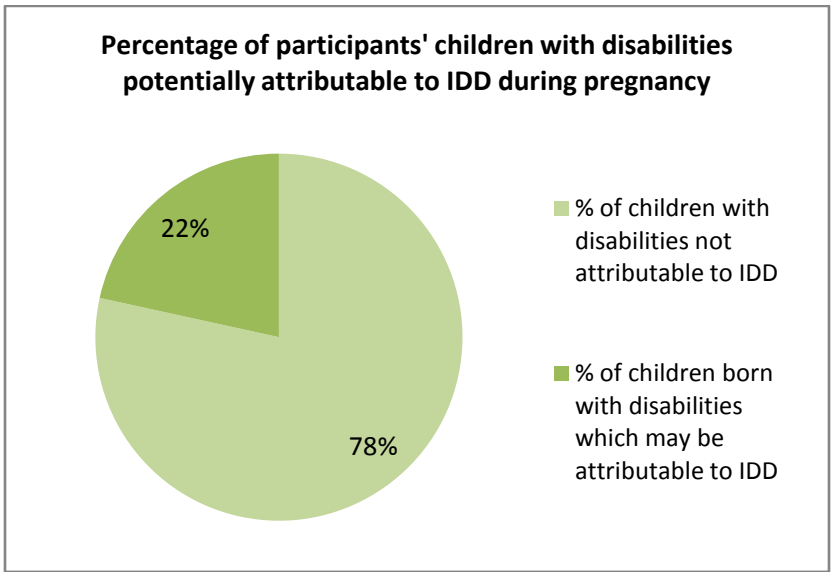


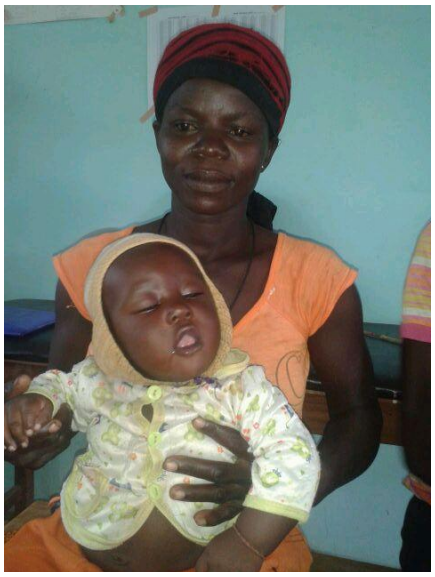
Follow-up diagnosis

The District Health Management Team agreed at the outset of the proposal for the goitre screening that a GHS-appointed clinician would carry out follow-up diagnosis of the suspected goitres detected amongst participants in each of the 7 CHPS zones. From the goitre screening carried out in September 2015, 62 women with suspected goitres and painful thyroids have been referred. Preparations for this phase of the project are in process and the results will be included in the final draft of this report.

Disabled children

As part of the screening process we asked participants whether they have or have had any children with a disability[5]. To determine whether participants had a child with a disability which may be attributable to IDD during pregnancy, we asked follow-up questions on whether the child can walk, talk, appears to have mental impairment or deformities and whether the condition appeared to be from birth or following illness. Based on these questions, 11 children's disabilities (22%), out of the 40 disabled children of the participants, may be attributable to damaged caused by preventable iodine deficiency during pregnancy (see chart below).





We had not included any activities to diagnose the childrens' disabilities as part of this goitre screening, so the data collated has been based solely on the answers provided by the mothers participating in the screening. Follow-up work would need to be carried out by a medical professional to verify the type and cause of their childrens' disabilities. However, our findings on the prevalence of iodine deficiency amongst women of child bearing age, coupled with the responses on their children's disabilities suggest there is high prevalence of IDD-attributable disabilities amongst children in the district.

It is worth noting, that according to UNICEF, most children born to iodine-deficient mothers appear normal although they may have suffered brain damage and loss in IQ points, which only becomes apparent later when they have difficulty learning in school. Further investigation into the levels of the pervasive effects of iodine deficiency in children in Lawra District from birth, through infancy and the early stages of childhood could be beneficial to inform iodine-interventions to tackle cognitive impairment in this target population.

[5] Definition of disability: "a physical or mental impairment that has a 'substantial' and 'long-term' negative effect on your ability to do normal daily activities." Equality Act 2010, https://www.gov.uk/definition-of-disability-under-equality-act-2010

Conclusions & Recommendations

Our findings show a suspected goitre prevalence rate of 5.3% amongst women in fertile age in Lawra District. This implies that chronic iodine deficiency among this population is at a level which could be considered a public health problem requiring greater investment in iodine interventions; most urgently in Boo CHPS Zone. Though the method we used for measuring goitre prevalence to infer chronic iodine deficiency was straight-forward, it is not sensitive to milder expressions of deficiency [24], therefore iodine deficiency in the district could be on an even larger scale.

We have also found that 40 children born to participants in this study have disabilities, and 22% of these disabilities are likely to have been caused by iodine deficiencies whilst developing in the womb. Without intervention, iodine deficiency will surely continue with profound health, social and economic costs and consequences for women, children and communities as a whole in Lawra District.

It is ATE's intention to share the findings of this study with our stakeholders to prompt interventions which reduce iodine deficiency disorder as a cause of disability, and promote nutrition of women in fertile age and healthy development of children in Lawra District. Steps must be taken to ensure that women consume iodised salt during pregnancy and breast-feeding so that their children are protected from the risks of severe disability and developmental delay, and are therefore afforded better chances to fulfill their potential. There is much evidence that correction of iodine deficiency has been followed by a "coming to life" of a community suffering from the effects on the brain of hypothyroidism due to iodine deficiency [28]. Such an increase in vitality is responsible for improved learning by schoolchildren, improved work performance of adults, and a better quality of life.

WHO strongly recommend the use of salt fortified with iodine in household and food production as the primary strategy for correcting and controlling iodine deficiency disorders [5]. For sustainable elimination of IDD, at least 90% of households would need to be using salt with an iodine content of 15 parts per million (ppm) or more [28]. This requires cross-sector political support, scale-up of fortification and supply of iodized salt, education to increase usage, and assessment and monitoring for changes. Thankfully Government-led plans for multi-sector national scale up and harmonization of nutrition programmes in Ghana are underway. However, WHO recognizes that in remote areas where communications are poor or where there are numerous very small-scale salt producers, iodisation of salt may not be a practical option for the sustainable elimination of IDD, at least in the short term [28]. In such areas, other options for correction of IDD may have to be considered while longer term sustainable solutions to eradicate IDD are put into place.

Iodine-supplying interventions

In remote areas, such as Lawra District, where we find there is a high prevalence of chronic iodine deficiency, we may wish to consider some iodine-supplying interventions, particularly for women in fertile age and the most affected communities, as follows:

- **High dose supplementation capsules:** Iodized oil taken orally has proven to be effective in treating and preventing iodine deficiency disorders [24]. One study estimates that "if every mother were to take iodine capsules, there would be a 7.5% increase in the total educational attainment of children in Central and Southern Africa. This, in turn, could affect the child's productivity throughout his or her life" [27]. Administration of iodine capsules are recommended every 6-18 months [24].

- **Iodine injections:** Injections of iodine can be effective for 3-4 years, however, there are draw backs as this requires trained personnel, and the use of needles which holds inherent risks of disease transmission [24]. Plus, the high cost per beneficiary (UK£0.53 to UK£1.83) means that this intervention is more suited to a defined number of individuals rather than whole communities. The cost of providing

iodine injections to the 62 women referred to a clinician as a result of the screening would be £32.86 to £113.46. To consider the intervention on a wider scale, injections for all 854 estimated women in fertile age in Boo, the CHPS Zone with the highest prevalence of goitre, would cost £452.62 to £1562.82.

- **Iodisation of water supplies** (by direct addition of iodine solution or via a special delivery mechanism): As the iodine content of plant foods depends on the iodine levels in soil and in groundwater used in irrigation, one promising option to tackle iodine deficiency across whole communities is to add potassium iodate to irrigation water [24]. Given that there is a limited irrigation in Lawra District the merits of applying this solution could also be explored for boreholes. Similar interventions have been carried out by adding iodine to borehole water in Mali [25].

Education and advocacy to increase usage of iodized salt

There is a general lack of awareness of the extent and severity of IDD. This must be corrected by systematically implementing campaigns to advocate, inform, educate and communicate. Following UNICEF and Bolgatanga Municipality Health Service's example, a programme of media advocacy targeted at consumers and traders on the importance of using adequately iodized salt could successfully increase household usage. Here are a few recommendations on how this could be achieved:

- **Radio advocacy:** Develop an ongoing education programme on local radio stations to inform consumers, particularly those in charge of preparing household meals, and traders about the important health benefits of iodized salt in preventing IDD, disability and impaired mental function, and how best to store salt to reduce iodine losses; in enclosed, waterproof containers. Correct misconceptions regarding differences in taste to common salt and encourage greater usage in households and food production [4].

- **Raise awareness at community meetings:** Deliver education on iodine deficiency disorder and the use of adequately iodized salt to control and prevent IDD with community leaders and families of disabled children in Lawra and Jirapa who meet on a monthly basis.

- **Work with small businesses:** Raise awareness of the importance of selling and using adequately iodized salt with small business owners, who sell salt and prepare food for sale. Advise traders on how to promote iodised salt to consumers. Advise salt traders on how to minimize losses of iodine from salt and provide iodine testing kits to ensure that the salt they sell is adequately iodized by the time it reaches local markets as salt which has lost most of its iodine will have no impact on IDD. The leading manufacturers of field test kits sell them for $0.50 per kit.

- **Networking:** Join relevant networks working to improve nutrition, food security and tackle causes of disability, in order to advocate for more investment in nutrition interventions, particularly for women in fertile age, infants, and children of school-going age in Lawra District and across the Upper West Region.

- **School feeding:** Educate school children on the importance of regular intake of iodised salt. As a result of the initial findings of this report, ATE is ensuring that adequately iodized salt is used in all schools benefitting from our school feeding programme. Ghana School Feeding Programme and local Education Offices could also ensure adequately iodized salt is used in all school meals provided across the district.

Data collection and monitoring impact of interventions

Steps must also be taken to measure the impact of interventions carried out and to sustain any progress made. This may involve ongoing, routine data collection, such as quality assurance of salt sold, measures of household use of iodized salt using iodine testing kits, and measures of iodine status amongst women in fertile age.

Goitre is not recommended for assessing the response to an intervention, as it can take months or years for goitre to reduce after iodine intake has normalised [26]. Instead, urinary iodine excretion (UIE), urinary iodine concentration (UIC) or measurement of dried blood spot thyroglobulin (Tg) are more effective indicators for baseline measurement and monitoring of thyroid function before and after iodine supply [5].

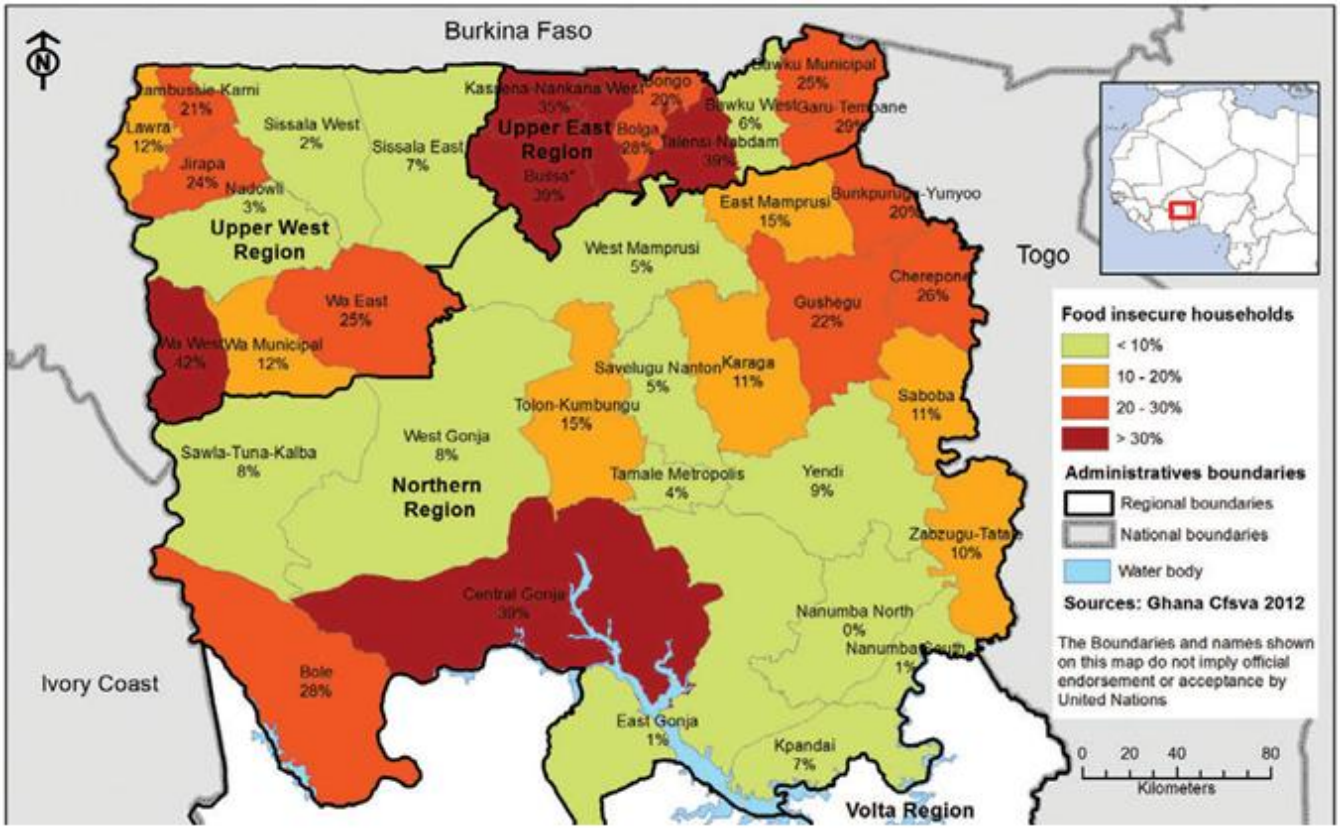
To take a UIE, UIC or Tg baseline for measuring interventions, a suggestion would be to use the opportunity to gain more in-depth data on prevalence of iodine deficiency amongst pregnant women, lactating women and school-age children in the district because these groups are described as the most vulnerable groups confronted by iodine deficiency disorders (WHO). ATE could work with medical professionals to carry out diagnoses of children with IDD induced disabilities, for further understanding of the scale of this issue and identify further children and families for support under the ATE Special Needs Awareness Programme.

Maps

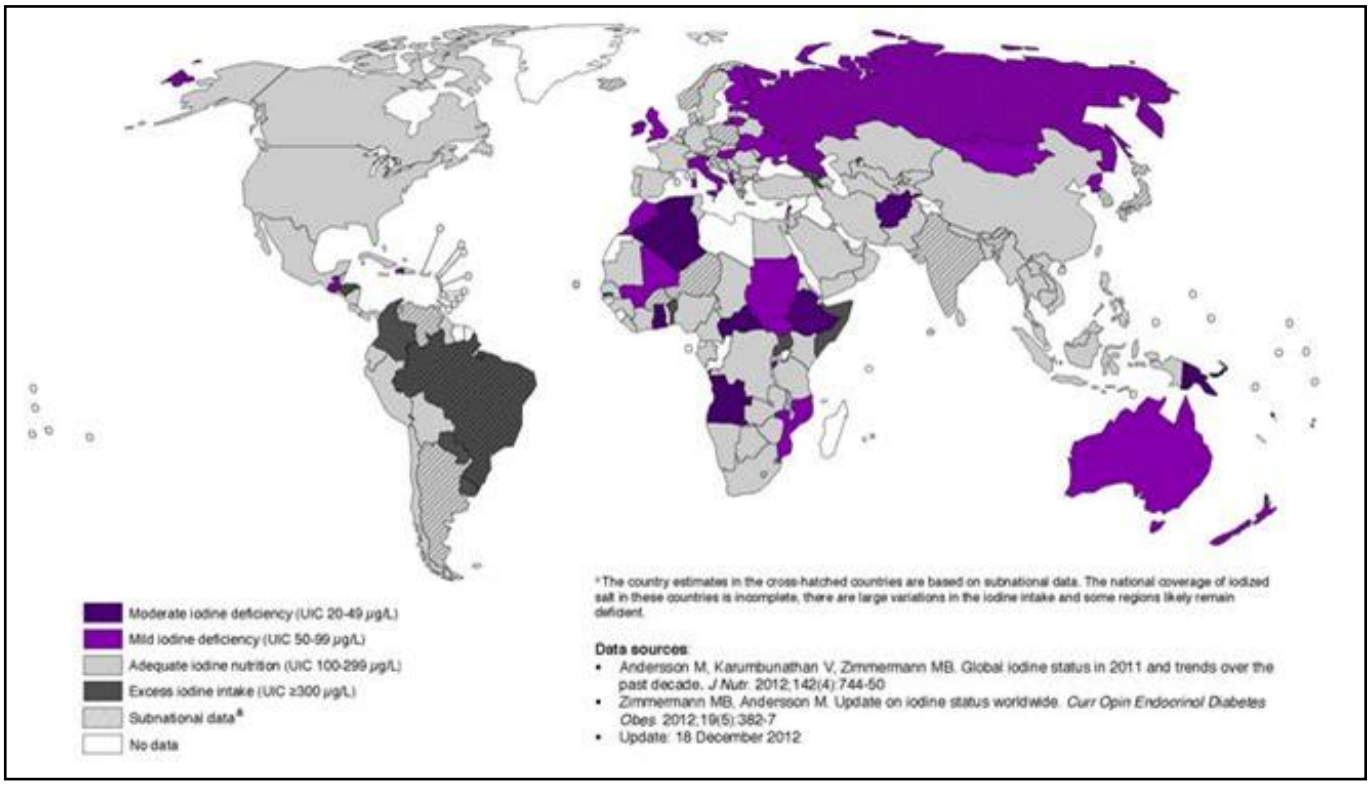
Map 1: Political Map of Ghana (nationsonline.org)

Map 2: District Map of Lawra (Source: GSS, GIS 2012)

Map 3: Map of Food Insecure Households in Northern Ghana 2012 (WFP) *Lawra District shown pre-split with Nandom



Map 4: National iodine status based on median UIC in school-age children (Source: IGN, Updated Dec 2012)



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Action Through Enterprise
CONSENT TO PARTICIPATE IN GOITER SCREENING

Representatives of the Action Through Enterprise charity (ATE) in partnership with Lawra District Health Department and CHPS compound staff are conducting a study into iodine deficiency among women of childbearing age through screening for goiters. You were selected as a participant in this study because you are a woman between the ages of 15 to 40 years old, living in Lawra District and you came forward for goiter screening. Your participation in this study is voluntary and you will not be paid for participating.

Why is this study being done?
This study is designed to find out the prevalence of iodine deficiency amongst women of child-bearing age in Lawra District. A lack of the right levels of iodine during pregnancy can cause multiple disabilities in offspring. This study may bring benefits to people in Lawra District as the results will highlight if there is a need for action to be taken to limit iodine deficiency as a cause of disability.

What will happen if I take part in this study?
If you volunteer to participate in this study, the ATE representative/CHPS staff will ask you to:

- Provide some personal details and inform us if you have any children born with disabilities
- Please note that any information obtained in connection with this study that can identify you will remain confidential.
- Allow a medical professional to palpate your neck to feel for evidence of a goiter
- Please note there are no anticipated risks or discomforts involved. If you would prefer a female medical practitioner to perform the palpitation please let this be known and we will try to accommodate your wishes.
- If a suspected goitre is detected you will be contacted to attend a voluntary follow up appointment with a clinician at your local CHPS compound to confirm the diagnosis.
- Please note that goiter cannot be cured.
- You have the right to choose to withdraw your consent and discontinue participation at any time.

Who can I contact if I have questions or concerns about this study?
ATE Operations Manager: Habib Albeboure, T: 0205096289 | E: habibalbeboure06@gmail.com
District Health Service Nutritionist, John Zenge, T: 0208394868 or Community Health Manager: Doris Nigre, T: 0208290687

This form will be read to you in Dagari and you will be given a copy to keep for your records.

Signature of study participant:

Name of Participant	Signature or thumbprint of Participant or Parent/Guardian	Date
If participant is under 18, name of person granting parental permission	Relationship to the participant	

Signature of person gaining consent:

Name of Person Obtaining Consent	Signature of Person Obtaining Consent	Date