



# CHAMPS

Identifying and addressing  
the excess burden of neural  
tube defects from CHAMPS  
Ethiopia: Transforming data  
to action



CHAMPS webinar series, 14<sup>th</sup> November  
2022



# Outline

- The problem of neural tube defects
- The size of the problem: prevalence of neural tube defects in Ethiopia
- Mortality attributed to neural tube defects in CHAMPS network
- Conclusions and Challenges with current estimates
- Neural Tube DefectS, Making sense of the unexpected
- The way forward in Ethiopia





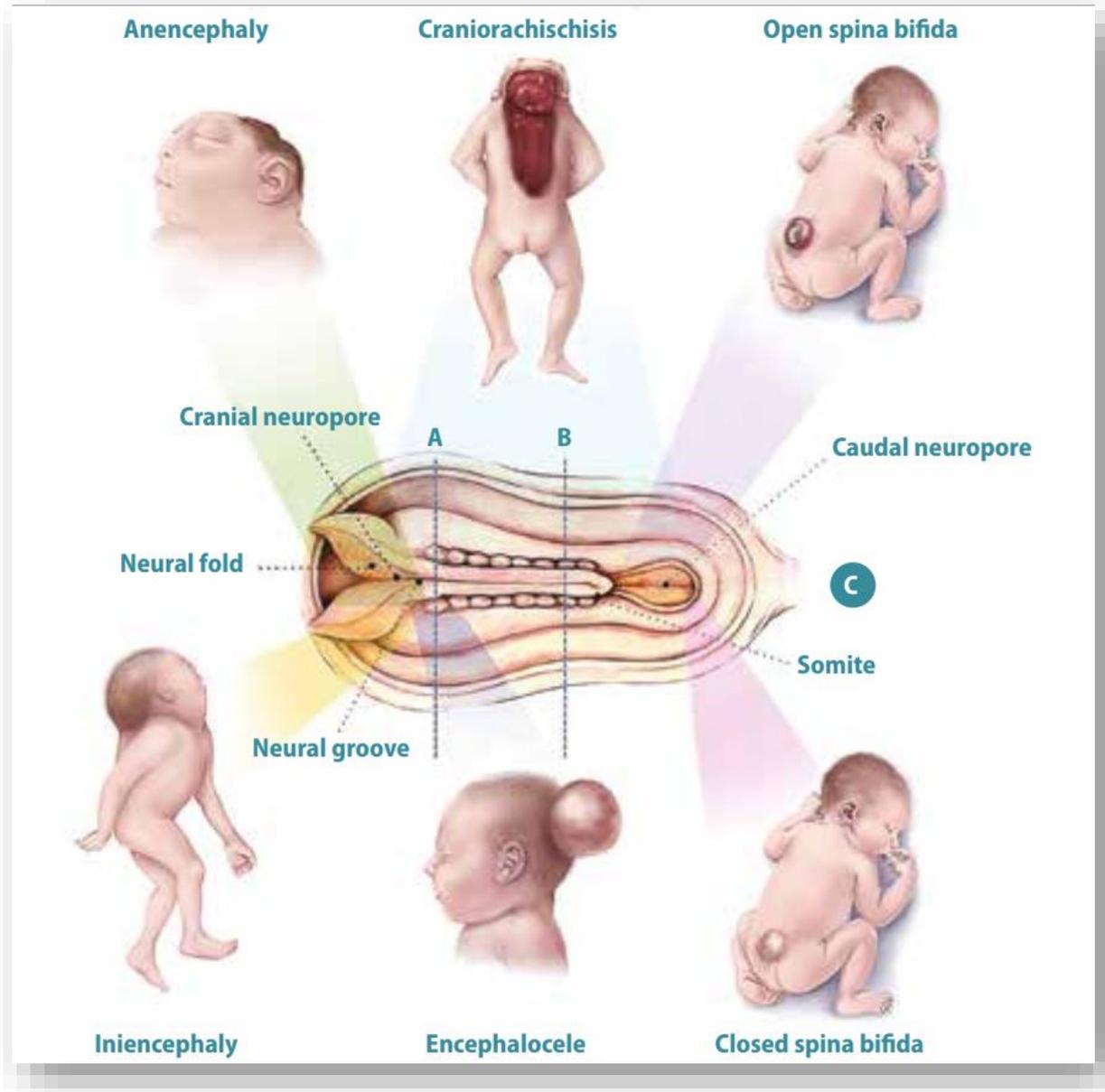
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## The problem of Neural Tube Defects



- Neural Tube Defects (NTDs) are one of the most common birth defects
- Due to incomplete closure of the embryonic neural tube between 21-28 days following conception
- Result in fetal loss and severe disability in children
- Most NTDs are related to folate deficiency in the mother
- Different types as shown in the figure





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**The size of the problem:  
prevalence of NTDs in Ethiopia**



# NTD prevalence - worldwide

Blencowe *et al.*

Worldwide neural tube defects: estimates for 2015

**Table 2.** Regional meta-analysis of overall birth prevalence of neural tube defects

Region	Number of studies	Overall NTD birth prevalence per 10,000 live births	95% Confidence intervals
Australasia	1	12.10	10.45–13.94
Latin America and the Caribbean: with folic acid fortification	12	7.78	6.58–8.97
Latin America and the Caribbean: without folic acid fortification	1	22.89	18.01–28.69
Eastern Europe and Central Asia	6	9.92	7.6–12.24
Sub-Saharan Africa: with folic acid fortification <sup>a</sup>	1	9.95	7.26–13.30
Sub-Saharan Africa: without folic acid fortification	6	15.27	10.19–20.34
East Asia	9	19.44	15.46–23.41
Northern Africa and Western Asia <sup>b</sup>	9	17.45	13.56–21.34
Europe	17	8.63	6.80–10.47
Southeast Asia <sup>c</sup>	2	6.76	5.77–7.75
North America	NA	Both countries in region have data	
Southern Asia <sup>d</sup>	11	31.96	23.81–40.12

<sup>a</sup>Based on a single South African study.<sup>1</sup>

<sup>b</sup>Studies are highly heterogeneous. Pooled regional data regardless of folic fortification (see Appendix S6, online only).

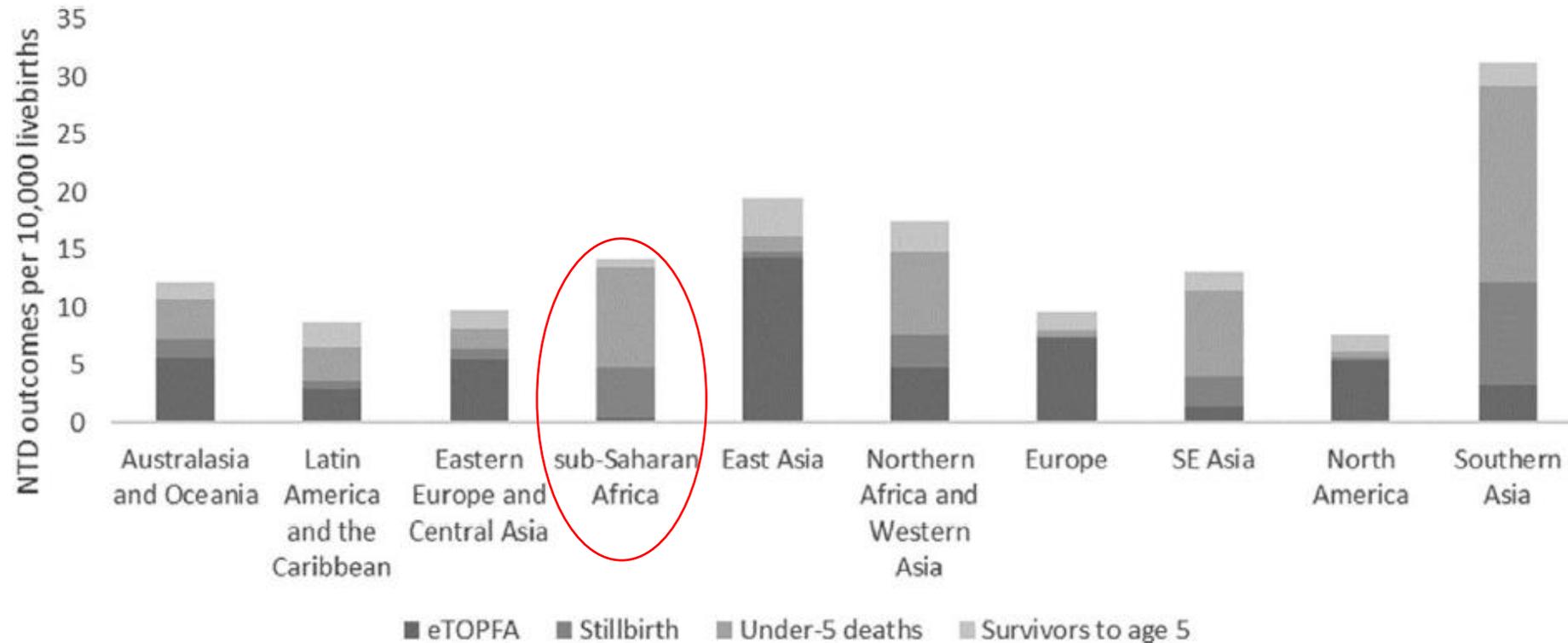
<sup>c</sup>Likely underestimate: used pooled hospital-based data from SEARO Newborn and Birth Defects Database in estimates.<sup>2</sup>

<sup>d</sup>Iran is the only country in the region with high coverage of folic fortification; we assumed that South Africa postfortification rates apply.<sup>1</sup>

# NTD prevalence - worldwide

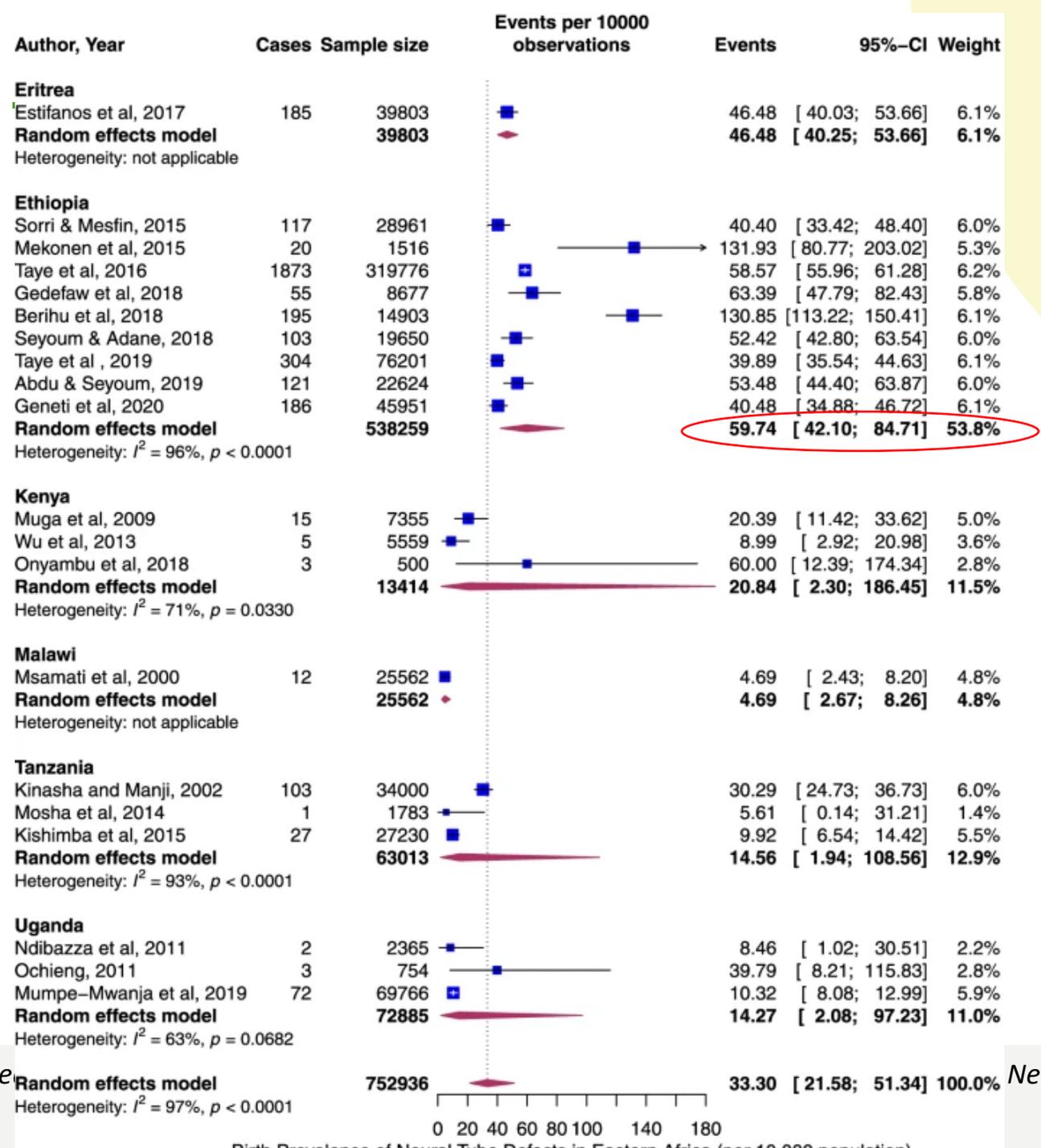
Worldwide neural tube defects: estimates for 2015

Blencowe *et al.*

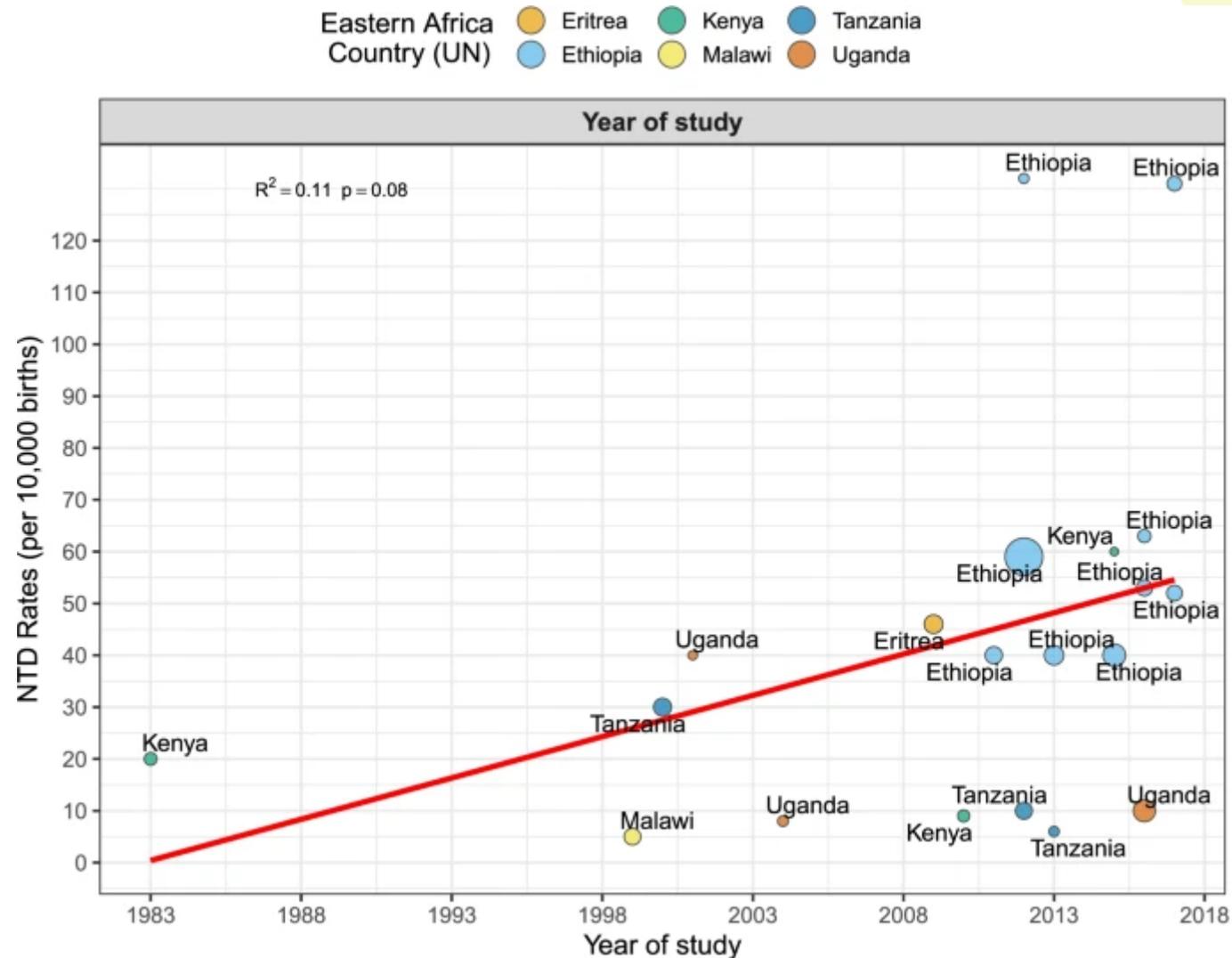


**Figure 3.** Regional stacked bar chart showing the estimated prevalence for NTD birth outcomes per 10,000 live births.

# NTD prevalence



# NTD prevalence – Eastern Africa



Birth prevalence of neural tube defects in eastern Africa: a systematic review and meta-analysis. Paddy Ssentongo et al. BMC Neurology (2022) 22:202

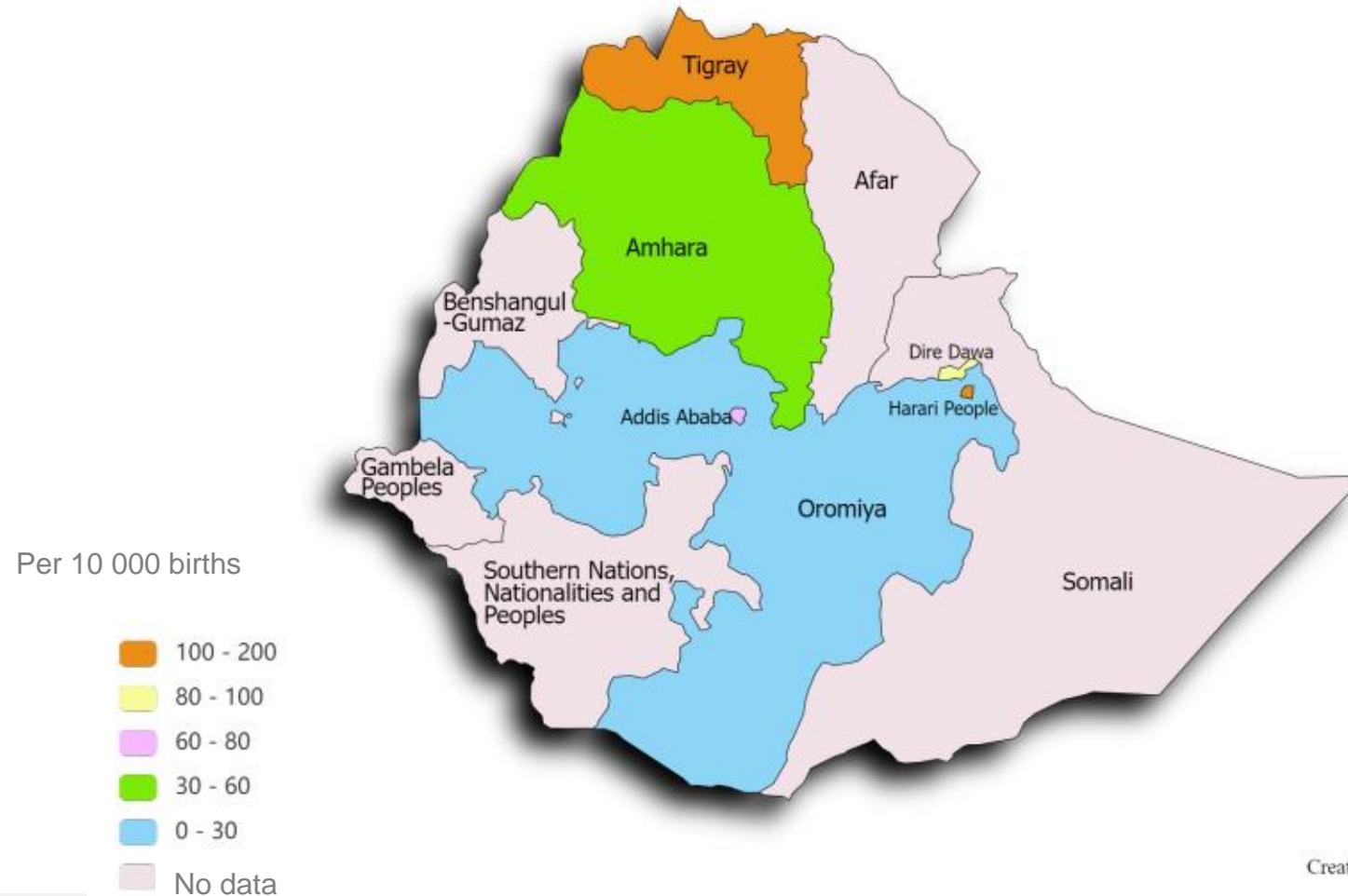
# NTD prevalence – Eastern Africa

Study	Country	Surveillance	NTD	Sample Size	Rate Per 10,000	Anencephaly	Spina Bifida	Encephalocele	Denominator	Quality Score
Mumpe-Mwanja et al., 2019 [36]	Uganda	Hospital-Based	72	69,766	10.3				live births, stillbirths and spontaneous abortion	6
Ndibazza et al., 2011 [37]	Uganda	Hospital-based	2	2365	8.5	1	1	0	live births and stillbirths	5
Ochieng 2011 [38]	Uganda	Hospital-based	3	754	39.8	0	3	0	live births	4
Onyambu et al., 2018 [39]	Kenya	Hospital-based	3	500	60.0	1	0	2	live births and stillbirths	5
Wu et al., 2013 [40]	Kenya	Community-based	3	5559	8.99	0	3	2	living children	5
Mosha et al., 2014 [33]	Tanzania	Community-based	1	1783	5.6	0	1	0	live births, stillbirths and spontaneous abortion	6
Muga et al., 2009 [41]	Kenya	Hospital-based	15	7355	20.4	10	4	1	live births and stillbirths	5
Kishimba et al., 2015 [34]	Tanzania	Hospital-based	27	27,230	9.9	14	10	3	live births	6
Gedefaw et al., 2018 [28]	Ethiopia	Hospital-based	55	8677	63.4	15	35	3	live births and stillbirths	5
Berihu et al., 2018 [29]	Ethiopia	Hospital-based	195	14,903	130.9	99	96		live births and stillbirths	6
Taye et al., 2019 [27]	Ethiopia	Hospital-based	304	76,201	39.9	36	268		living children (0–17 y)	6
Geneti et al., 2019 [31]	Ethiopia	Hospital-based	186	45,951	40.5	63	33	4	live births and stillbirths	6
Seyoum & Adane, 2018 [30]	Ethiopia	Hospital-based	103	19,650	52.4	7	53		live births and stillbirths	6
Sorri & Mesfin, 2015 [24]	Ethiopia	Hospital-based	117	28,961	40.4	77	95	5	live births and stillbirths	4
Taye et al., 2016 [26]	Ethiopia	Hospital-based	1873	319,776	58.6	163	995	25	living children (0–17 y)	4
Msamati et al., 2000 [43]	Malawi	Hospital-based	12	25,562	4.7		12		live births	5
Kinasha and Manji, 2002 [35]	Tanzania	Hospital-based	103	34,000	30.3	4	89	10	live births	5
Estifanos et al., 2017 [42]	Eritrea	Hospital-based	185	39,803	46.5	75	27		live births and stillbirths	6
Mekonen et al., 2015 [25]	Ethiopia	Hospital-based	20	1516	131.9	1	19		live births	5
Abdu & Seyoum, 2019 [32]	Ethiopia	Hospital-based	121	22,624	53.5		121		live births	5

Most hospital-based.  
All Ethiopian studies  
were hospital-based

# NTD prevalence – Ethiopia

NTD prevalence in Ethiopia



National pool prevalence  
63 per 10 000 children

Created with paintmaps.com

# NTD prevalence – Ethiopia

**Table 1.** Detailed Description of the Included Studies for Computing the Magnitude of Neural Tube Defects (NTDs) in Ethiopia.

Author, year	Study area	Study design	Study population	Sample size	NTDs/10 000 children	Patterns of NTDs			Quality score
						Anencephaly/10 000 children	Spinal bifida/10 000 children	Encephalocele/10 000 children	
Berihu et al, <sup>23</sup> 2018	Tigray	Cross-sectional	Newborns	14 903	130.8	66.4	64.4	—	Medium
Seyoum and Adane, <sup>31</sup> 2018	Amhara	Cross-sectional	Newborns	19 650	35.6	5.1	30.5	—	Medium
Gedefaw et al, <sup>26</sup> 2018	Addis Ababa	Cross-sectional	Newborns	8677	127.9	69.1	51.9	6.91	High
Sorri and Mesfin, <sup>27</sup> 2015	Addis Ababa	Cross-sectional	Newborns	28 961	61.1	26.6	32.8	1.73	Medium
Taye et al, <sup>24</sup> 2019	Addis Ababa and Amhara	Cross-sectional	0-17 years	76 201	47.5	4.7	42.8	—	High
Taye et al, <sup>29</sup> 2016	Addis Ababa and Amhara	Cross-sectional	0-17 years	319 776	37.6	5.7	31.1	0.78	Medium
Mekonen et al, <sup>36</sup> 2015	Tigray	Cohort	Newborns	1516	131.9	6.6	125.3	—	Medium
Abdu and Seyoum, <sup>37</sup> 2019	Amhara	Cross-sectional	Newborns	22 624	53.5	—	53.5	—	Medium
Abebe et al, <sup>38</sup> 2019	Oromia	Cross-sectional	Newborns	45 951	25.7	13.7	11.1	0.87	Medium
Mitiku, <sup>39</sup> 2017	Addis Ababa	Cross-sectional	Newborns	84	281.1	238.1	—	—	Medium

ALL hospital-based.



True prevalence UNKNOWN



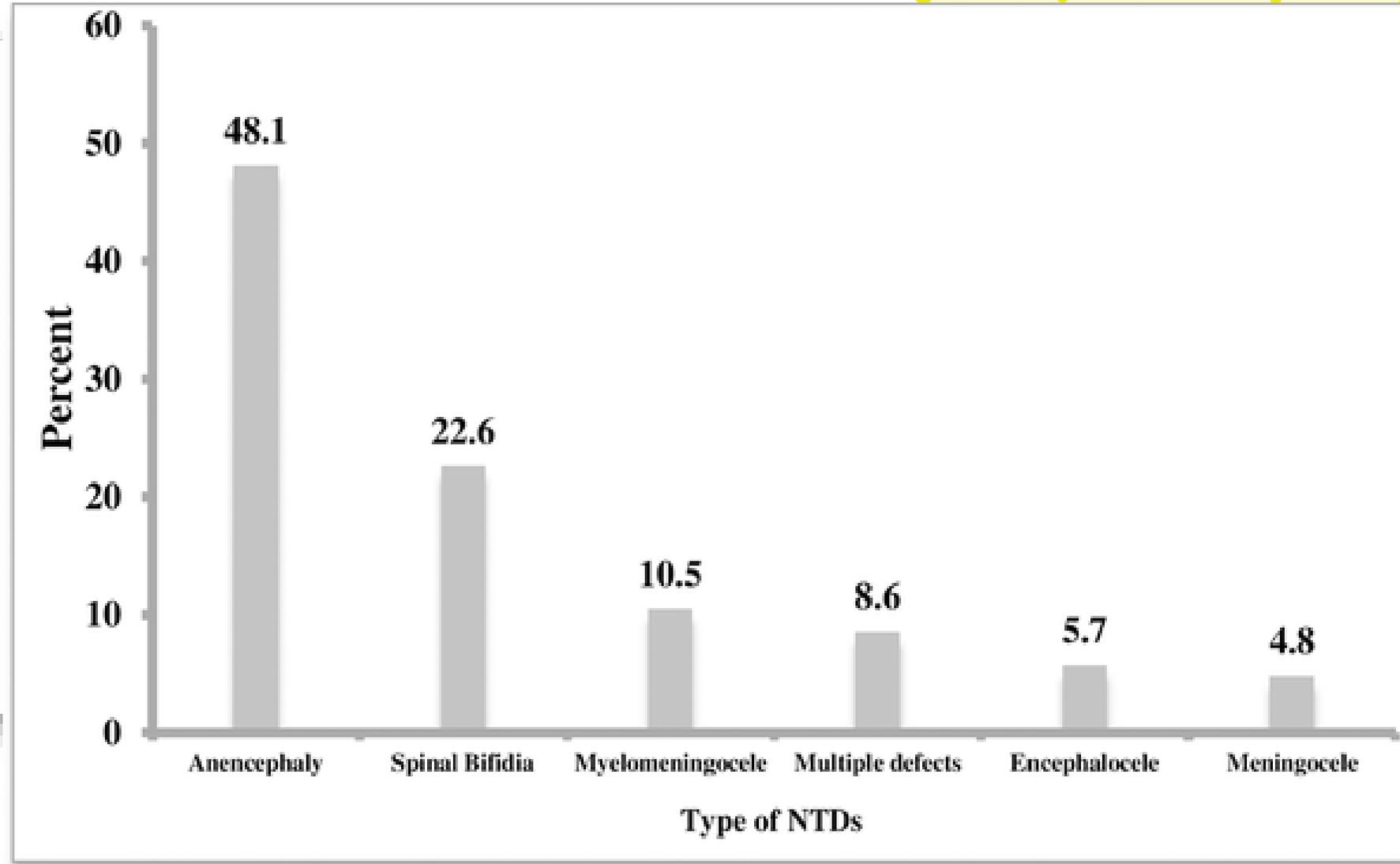
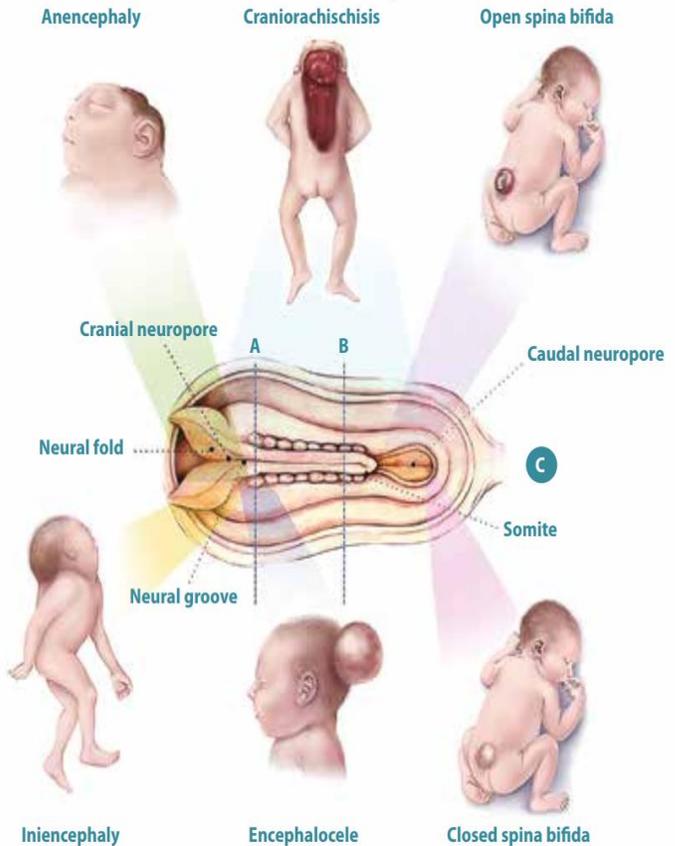
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Prevalence of neural tube  
defects in Ethiopia by type



# Prevalence of Type of NTDs in Ethiopia



Berhane A, Belachew T (2022) Trend and burden of neural tube defects among cohort of pregnant women in Ethiopia: Where are we in the prevention and what is the way forward?. PLOS ONE 17(2): e0264005. <https://doi.org/10.1371/journal.pone.0264005>



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**Mortality attributed to neural tube  
defects in CHAMPS**

<https://champshealth.org/>

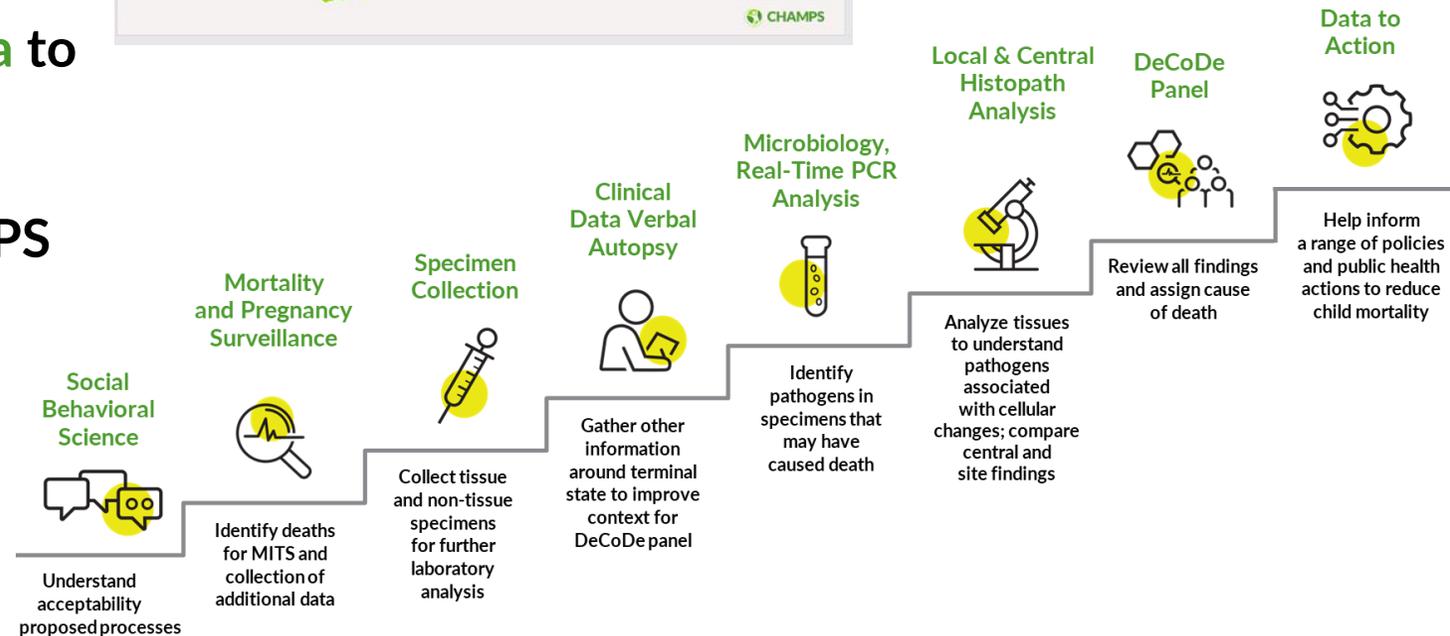


# CHAMPS Network – Overarching Objectives

Track definitive causes of child mortality in sites throughout Sub-Saharan Africa and South Asia

Produce and disseminate high-quality data to inform policy and public health action

Enable sites to be able to leverage CHAMPS investment to prevent mortality



# Conclusions and challenges with current estimates

The prevalence in Ethiopia is much higher than in other countries worldwide and in sub-Saharan Africa

All data are from hospital-based studies likely overestimating the burden of NTD among children born alive

Scarcity of data for abortions and stillbirths, that may account up to 50% of all NTDs

True prevalence is unknown due to the problems stated above





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Neural Tube Defect,  
Making sense of the unexpected



# Background

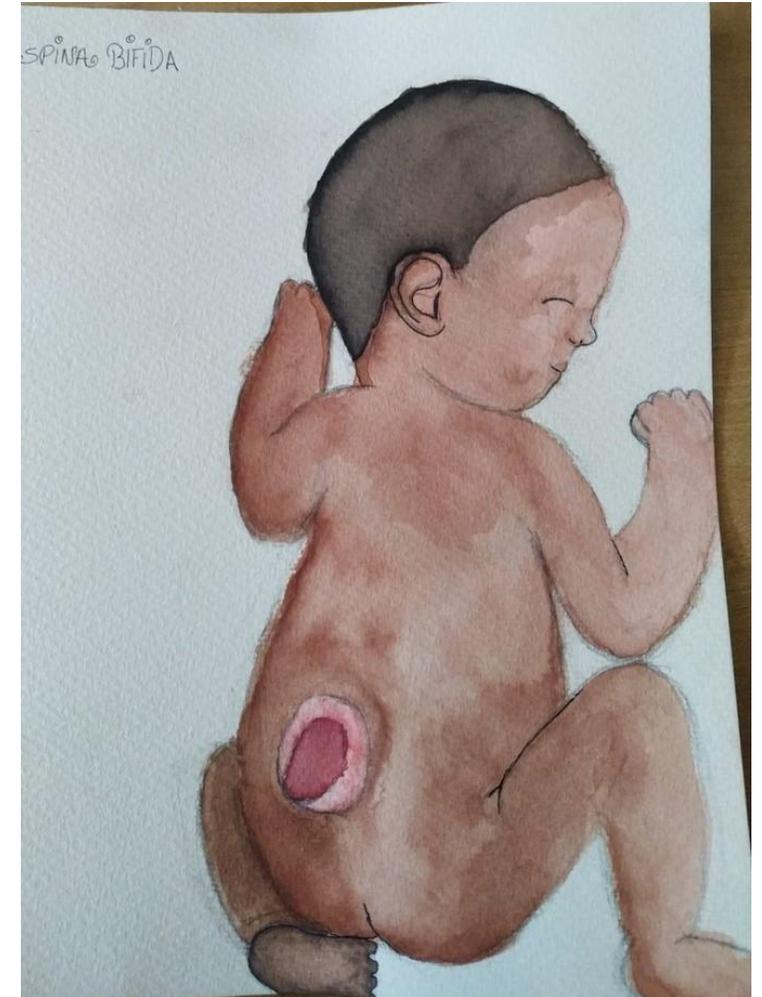
- There is little knowledge about how people in eastern Ethiopia understand the causes of NTDs.



# Methods

Qualitative research by the CHAMPS SBS team in Harar

- Interviews
  - Seven mothers to babies born with NTDs
  - Two traditional birth attendants
  - Seven health workers
- Focus group discussions
  - Two with women (16 in total)
  - One with ten men
- Collaborative data analysis process



## Results I: Allah's will

Menida had given birth to a baby with 'two holes in the back' (spina bifida). The baby was stillborn and she said:

*'I don't know how to explain what happened to my baby. Allah knows everything. I have never before heard about or seen something similar to what happened to my baby.'*

Menida did not have any knowledge about the NTDs or their causes:

*'I guess nothing about why this happened except that is Allah's will. I have never thought that there is something is wrong with me. This happened because of Allah's will.'*

## Results II: Punishment for bad behaviour

- *‘Many people believe that the husband or wife or their families have done something wrong which led to the problem. The community says that a child is born with malformation because its family has sinned against Allah. Some say that the father is getting payment for what he has done. Elders advise that people shouldn’t laugh at someone who has physical problems. If they do so, it can happen to their family.’ [Traditional birth attendant]*

## Results III: Natural explanations

*'Sometimes I think that the problem is related to something that might happen naturally and sometimes I think that it might be due to my negligence in relation to some specific activities I did. While I was pregnant, I used to carry my older child and sometimes I think this might have led to the problem.'* [Mother]

*'Because of lack of awareness, sometimes, they blame us health professionals. They don't have formal education and their views are very different from ours. Some people say that we have killed their child unless someone was there watching the delivery. They think as if the damage happened during delivery.'* [Health center worker]

# Conclusion

- Understanding of NTDs depended on people's positions.
- People's views differ from scientific understandings of NTDs
- Local perceptions cannot be ignored in attempts to reduce NTDs



# Moving forward in Ethiopia

- Further research to explore more about the different kinds of NTDs, how people live with NTDs, behaviour towards people living NTDs, existing support for families, etc.
- Formative research is necessary for clinical projects on NTDs to find ways to work with communities on this sensitive topic.
- We need to find new ways to disseminate scientific knowledge about the underlying causes and prevention.



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**The way forward**



# Data-to-action activities related to NTDs

CHAMPS is implementing a NTD surveillance at the population level in Eastern Ethiopia (3 hospitals, 20 health centres and a community of >300 000 people)

It will generate data before and after a mandatory food fortification program is well implemented in Ethiopia

The experience of CHAMPS with this surveillance may serve as an example to implement surveillance across the country

We are working with the main hospital in the area to create a multidisciplinary team to improve the care of children living with NTD

The project will also explore the feasibility and acceptability of a food fortification program with fortified salt (to be validated as a food vehicle) and community perceptions on NTDs and stigma

# CHAMPS Ethiopia intervening on NTD

NTD

- Unlocking the silence in the community
- Guidance and Counseling
- Folic acid distribution
- Health professional capacity building
- Follow up and linkage with hospital
- Community and health facility pilot surveillance on NTD



## Future plan

- Comprehensive awareness raising
- Continuous guidance and counseling
- Linkage for live children with NTD.  
For some families, full related costs will be covered.
- Folic acid distribution for families

# They way forward to estimate true prevalence

CHAMPS is implementing a NTD surveillance at the population level in Eastern Ethiopia (3 hospitals, 20 health centres and a community of >300 000 people)

It will generate data before and after a mandatory food fortification program is well-implemented in Ethiopia. The experience of CHAMPS with this surveillance may serve as an example to implement surveillance across the country

We will do a survey to know the folic acid deficiency among WRA in our catchment area.

We are working with the main hospital in the area to create a multidisciplinary team to improve the care of children living with NTD

The project will also explore the feasibility and acceptability of a food fortification program with fortified salt (to be validated as a food vehicle) and community perceptions on NTDs and stigma



# CHAMPS



To learn more about CHAMPS contact us at [info@champshealth.org](mailto:info@champshealth.org)