CDC PUBLIC HEALTH GRAND ROUNDS

Global Prevention of Neural Tube Defects

October 17, 2017

U.S. Department of Health and Human Services
Centers for Disease Control and Prevention

Prevention of Neural Tube Defects

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U.S. Department of Health and Human Services
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Neural Tube Defects (NTDs)

Spina Bifida, high lesion

Spina Bifida, sacral lesion

Anencephaly

Encephalocele

- **Failure of the neural tube to close causes neural tube defects**
- **Neural tube forms very early in pregnancy, first days through day 28 of gestation**
- **Interventions to prevent must take place prior to neural tube closure, often before woman is aware of pregnancy**
  - ~50% unplanned pregnancy rate in the U.S.

who.int/nutrition/publications/birthdefects_atlas/en/

Living with Spina Bifida

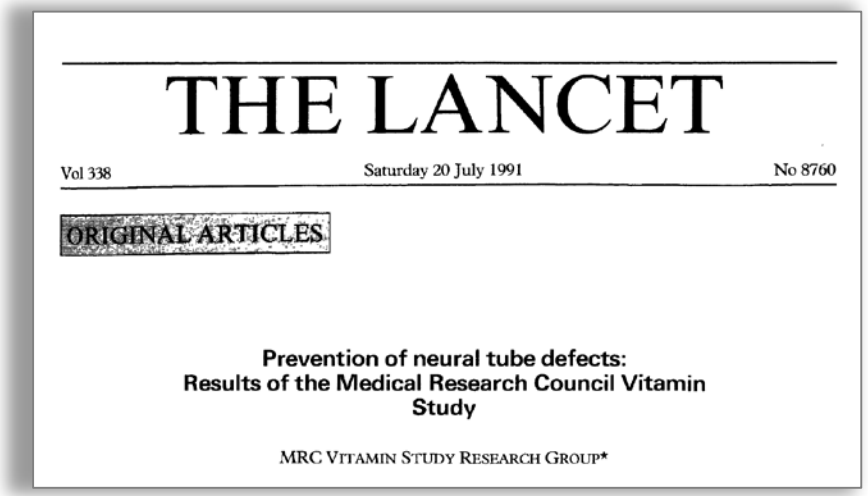
- **With intervention, such as surgery or assistive medical equipment, people with spina bifida can live full and productive lives**
- **Lifelong disability**
  - Mean direct lifetime cost in US estimated to be **~$800,000**
- **Impacts the individual, family, and society**
- **Prevention would result in tremendous health and financial benefit**

Grosse SD, Berry RJ, Mick Tilford Jet al. Am J Prev Med. 2016 May;50(5 Suppl 1):S74-80

Folate, Folic Acid, and Anemia

- **Folate (vitamin B9) is critical to basic processes in the body such as DNA replication and DNA, RNA, and protein methylation**
- **Folate is a general term used to describe the many different forms:**
  - Folic acid, dihydrofolate (DHF), tetrahydrofolate (THF), 5, 10-methylenetetrahydrofolate (5, 10-MTHF), and 5-methyltetrahydrofolate (5-MTHF)
- **Folic acid is a synthetic form of folate that, unlike natural food folate (generally 5-MTHF), is not easily degraded by heat or light**
- **Initially folic acid was used to treat megaloblastic anemia**

Randomized-controlled Trials Demonstrate Folic Acid Supplements Can Prevent Neural Tube Defects


THE LANCET

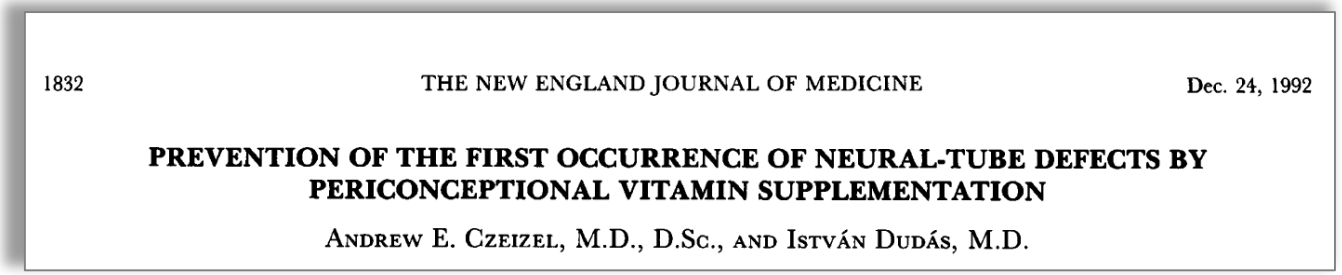
Vol 338 Saturday 20 July 1991 No 8760

ORIGINAL ARTICLES

Prevention of neural tube defects: Results of the Medical Research Council Vitamin Study

MRC VITAMIN STUDY RESEARCH GROUP*

- **1991: Among women with a previous NTD-affected pregnancy (n=1817)**
  - 4,000 micrograms (µg)/day supplement containing only folic acid
  - 72% reduction in NTDs


1832 THE NEW ENGLAND JOURNAL OF MEDICINE Dec. 24, 1992

PREVENTION OF THE FIRST OCCURRENCE OF NEURAL-TUBE DEFECTS BY PERICONCEPTIONAL VITAMIN SUPPLEMENTATION

ANDREW E. CZEIZEL, M.D., D.SC., AND ISTVÁN DUDÁS, M.D.

- **1992: Among women without a history of NTD-affected pregnancies (n=4753)**
  - 800 µg/day multivitamin supplement containing folic acid

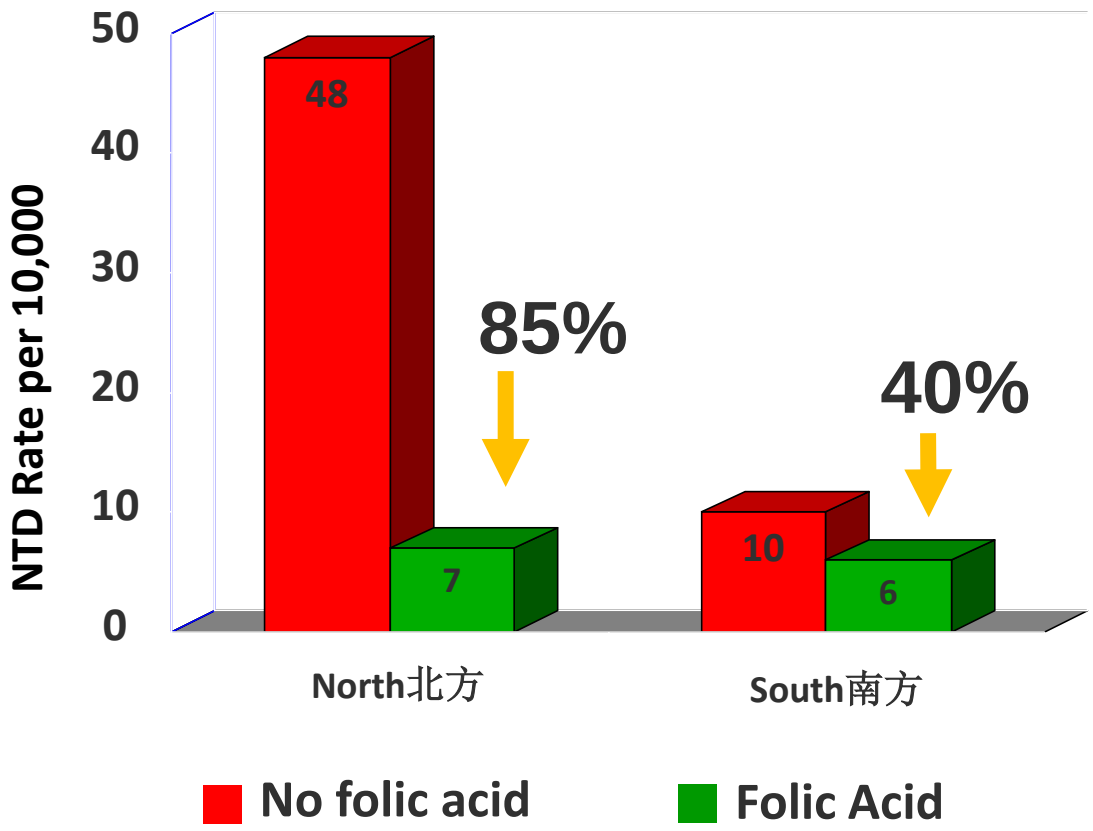
MRC Vitamin Study Research Group. Lancet. 1991 Jul 20;338(8760):131-7
Czeizel AE, Dudás I. N Engl J Med. 1992 Dec 24;327(26):1832-5

Prevention of Neural Tube Defects
Evidence from a Community Trial: China (1993-1996)

- Intervention = 400 µg/day (folic acid only)
- Women enrolled during premarital examination
- Included 247,831 pregnancies
- 275 NTDs

Berry RJ, Li Z, Erickson JD, et al. N Engl J Med. 1999 Nov 11;341(20):1485-90

Prevention of Neural Tube Defects
Evidence from a Community Trial: China (1993-1996)



Periconceptional use, high compliance

- In the high-risk northern counties, NTD prevalence reduced by 85%
- In the moderate-risk southern counties, NTD prevalence reduced by 40%
- Showed that percent reduction in NTDs is dependent on baseline rates
- 400 µg/day folic acid alone could reduce risk but did not prevent all occurrences
  - NTDs can be caused by other conditions such as chromosomal anomalies

Berry RJ, Li Z, Erickson JD, et al. N Engl J Med. 1999 Nov 11;341(20):1485-90

Prevention Recommendations in the United States

- **In 1998, to reduce the risk of neural tube defects the Institute of Medicine recommended that women capable of becoming pregnant should take 400 micrograms of synthetic folic acid daily**
  - From fortified foods or supplements or a combination of the two, in addition to consuming food with natural folate from a varied diet

- **In 2017, U.S. Preventive Services Task Force**
  - 400–800 µg/day of folic acid from supplements
  - Grade of A (highest level of confidence)

Challenges with Preventing Neural Tube Defects

- **Timing**
  - Women must consume folic acid supplements prior to conception and continue in early pregnancy
    - ~50% unplanned in US
- **Vehicle**
  - Difficult to achieve the equivalent of 400 µg folic acid through dietary food folate intake and requires behavioral change
    - 18 cups raw spinach
    - 31 spears of boiled asparagus
    - 7 1/2 cups canned kidney beans
  - Folic acid is the only form of folate that has been shown in clinical trials to prevent neural tube defects
- **Delivery**
  - Folic acid containing supplements are not widely consumed
  - Need to reach the highest risk women

ods.od.nih.gov/factsheets/Folate-HealthProfessional/

cdc.gov/ncbddd/folicacid/faqs/faqs-general-info.html

Ray JG, Singh G, Burrows RF. BJOG. 2004 May;111(5):399-408

Fortify Foods with Folic Acid
An Alternative Approach to Prevent Neural Tube Defects

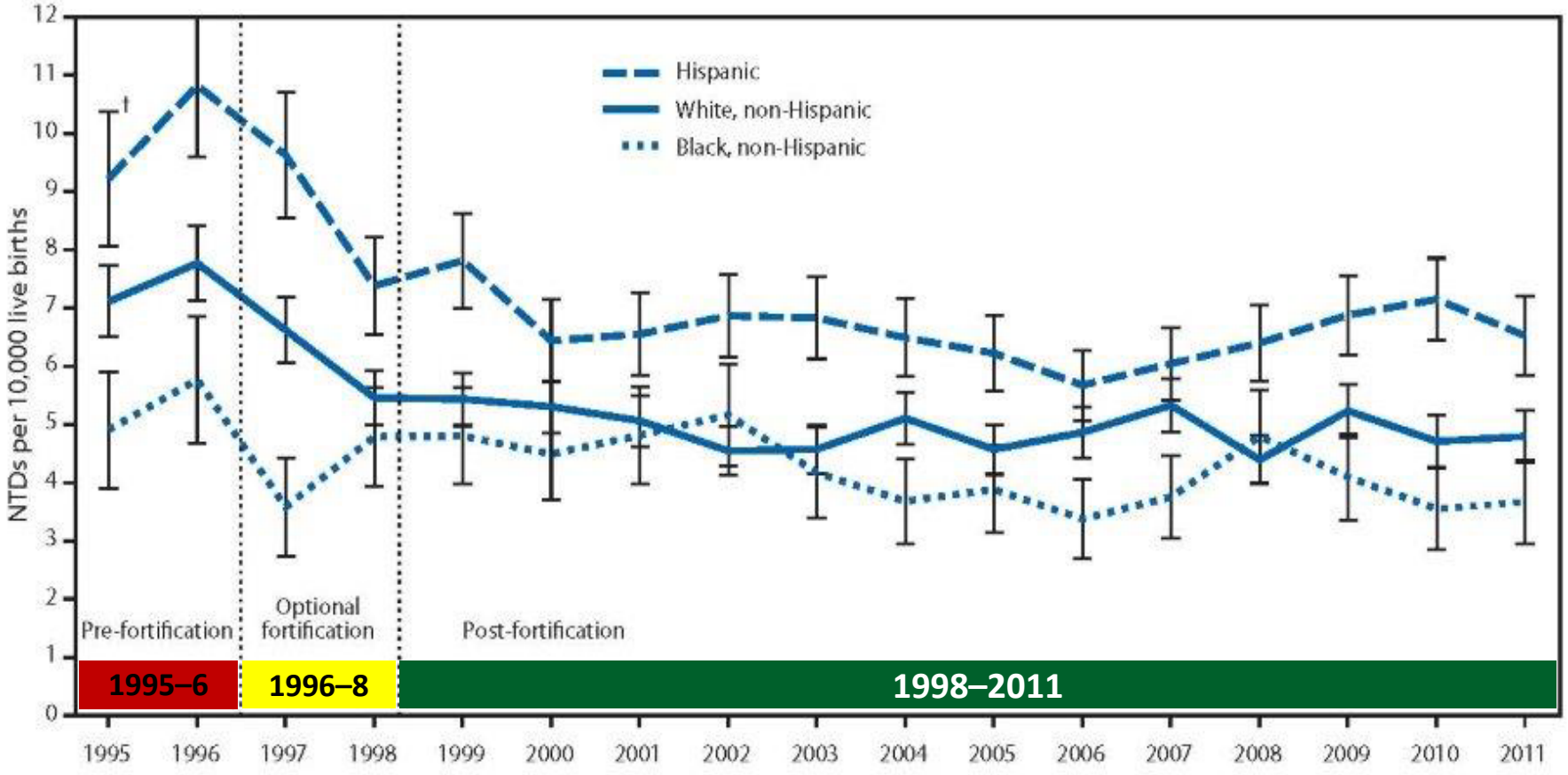
- **Folic acid fortification of enriched cereal grain products**
  - Folic acid reduces the risk of NTDs
  - Folic acid is stable to heat and light (baking and storage)
  - Products already fortified with other micronutrients
  - Products consumed regularly, so no behavior change needed

- **1998: Cereal grain products labeled as enriched were required to contain 140 micrograms (µg) folic acid for every 100 g product**

ods.od.nih.gov/factsheets/Folate-HealthProfessional/
cdc.gov/ncbddd/folicacid/faqs/faqs-general-info.html

Folic Acid Fortification and Neural Tube Defects (NTDs)

Prevalence of Anencephaly and Spina Bifida in U.S., 1995–2011

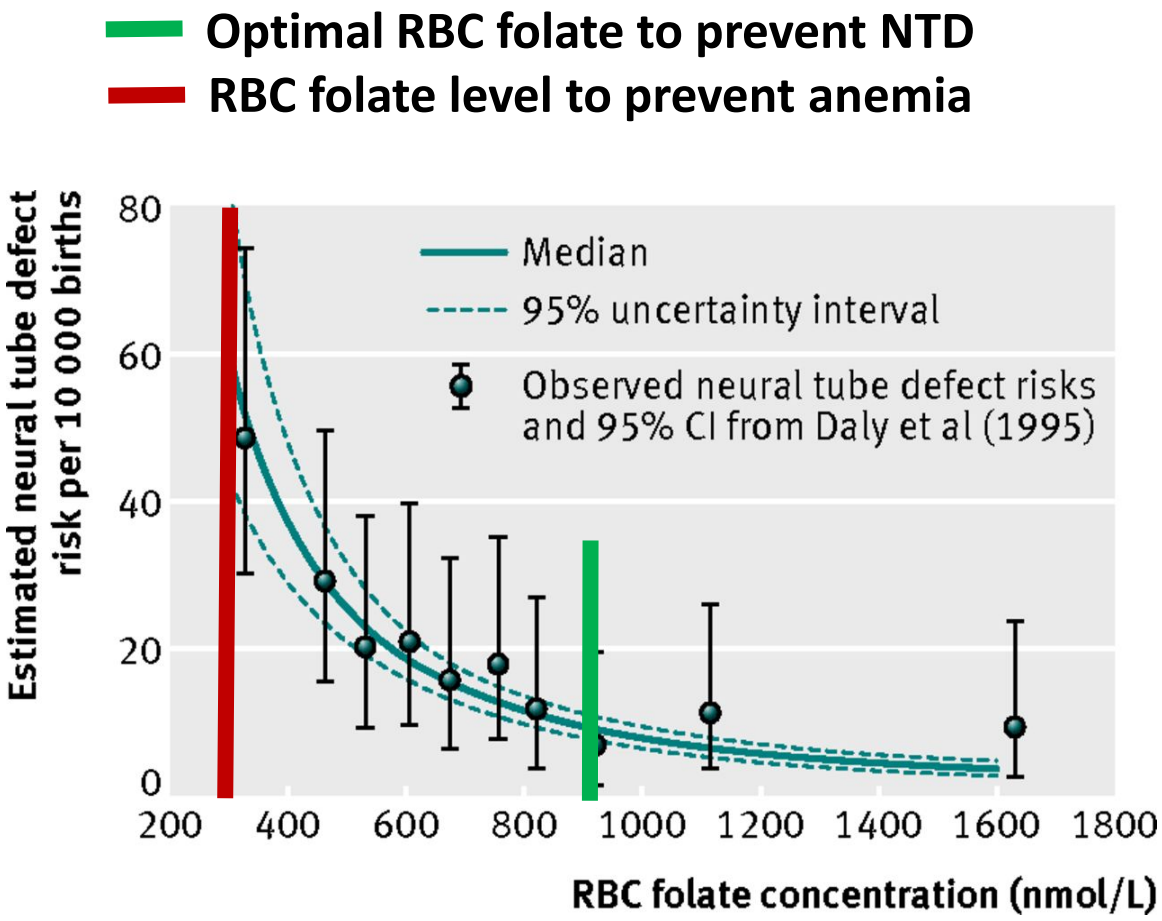


- **35% reduction in occurrence of NTDs post-fortification**
  - Who is the intervention reaching?
  - How to reduce more?
  - How best to target further interventions?

* Anencephaly and spina bifida only, some programs without prenatal ascertainment

Williams J, Mai CT, Mulinare J, et. al. MMWR. 2015 Jan 16;64(1):1-5

Red Blood Cell (RBC) Folate Concentration As a Biomarker of Risk of Neural Tube Defects in Populations



- As RBC folate concentrations increase, NTD risk decreases
- In 2015, WHO recommended optimal RBC folate concentration threshold in populations for NTD prevention in women of reproductive age
  - 906 nmol/L (400 ng/ml)
- Deficiency RBC folate concentration for prevention of anemia in the general population
  - 305 nmol/L

Crider KS, Devine O, Hao L, et. al. BMJ. 2014 Jul 29;349:g4554
who.int/nutrition/publications/guidelines/optimalserum_rbc_womenrep_tubedefects/en/

Using WHO-Recommended RBC Folate Concentration to Inform Folic Acid Interventions

1. Assess
Measure RBC folate concentration distributions (microbiologic assay)

2. Identify
Determine the need for intervention

3. Target
Best approach to reach your high-risk populations

4. Implement
Implement the intervention

5. Evaluate
Reassess population RBC folate concentrations 6 to 12 months post-intervention

6. Adjust
Adjust program/intervention based on data

Three Current Sources of Folic Acid in the US

- **Mandatory:** cereal grain products labeled as enriched (**ECGP**) must contain 140 µg folic acid for every 100 g of product

- **Voluntary:** ready to eat cereals (**RTE**) can have up to 400 µg folic acid per serving

- **Supplements** (**SUPP**)**:** usually contain 400-800 µg folic acid

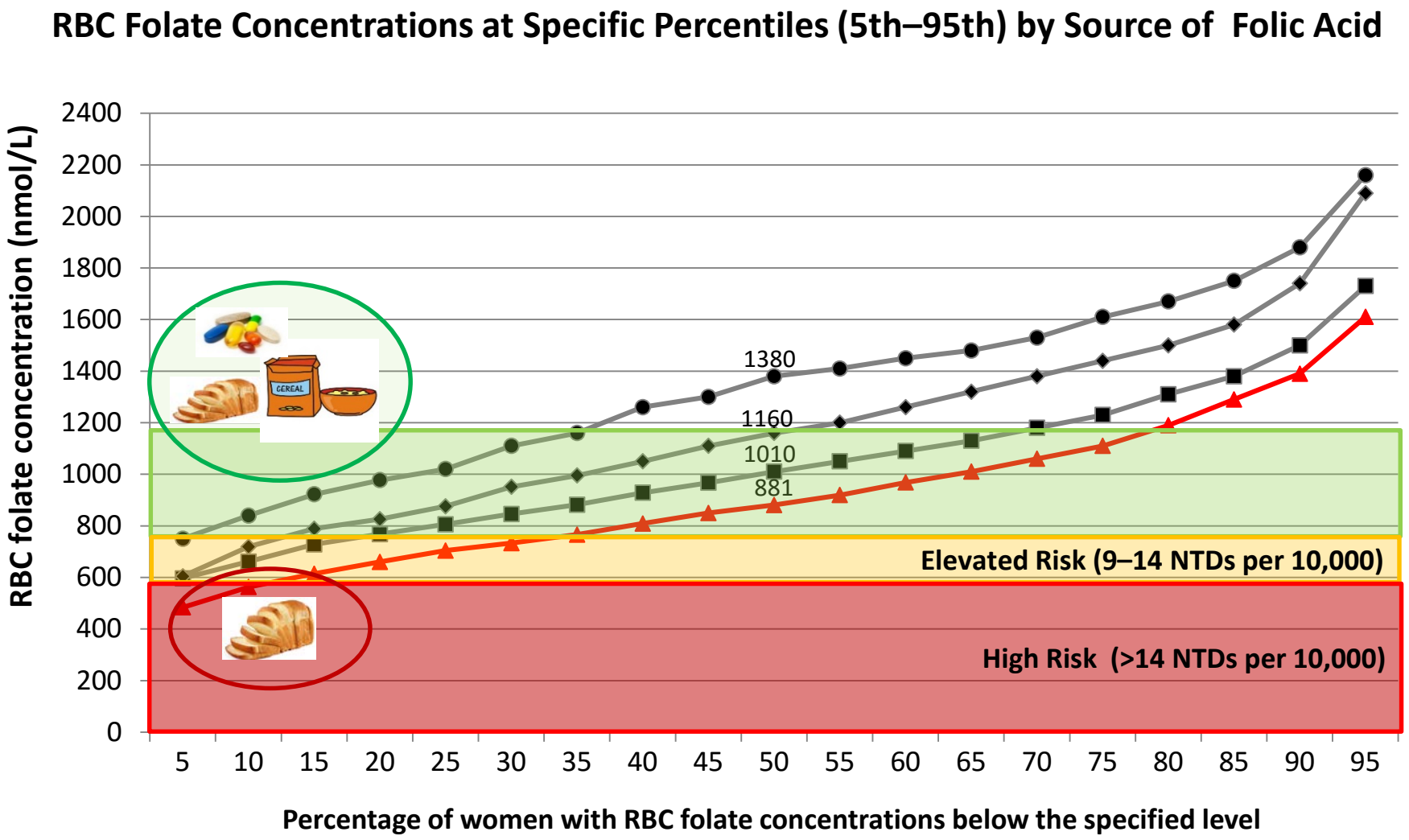
Using WHO Recommended RBC Folate Concentration in the US

- **RBC folate concentrations in U.S. women age 12-49 years, NHANES (2007–2012)**
- **Majority of U.S. women at or above the optimal RBC folate concentration threshold**
- **23% of U.S. women have suboptimal RBC folate concentrations**

Risk category	NTD prevalence	RBC folate concentration (NHANES assay)	Percentage of population
High	>14 per 10,000	<585 nmol	**8%**
Elevated	9–14 per 10,000	586–747 nmol	**15%**
Optimal	4–<9 per 10,000	748–1216 nmol	**46%**
Limited additional benefit	Outside estimable range	≥1216 nmol	**31%**

Tinker SC, Hamner HC, Qi YP, Crider KS. Birth Defects Res A Clin Mol Teratol. 2015 Jun;103(6):517-26. Epub 2015 Apr 17

Women with Suboptimal RBC Folate Concentrations Are More Likely to Have Only One Source of Folic Acid



- 48% of women of reproductive age have enriched cereal grain products (ECGP) as their only folic acid source

ECGP only
ECGP+RTE cereals
ECGP+SUPP
ECGP+RTE+SUPP

Tinker SC, Hamner HC, Qi YP, Crider KS. Birth Defects Res A Clin Mol Teratol. 2015 Jun;103(6):517-26. Epub 2015 Apr 17

Reaching Those at Higher Risk for NTDs

- **The optimal RBC folate concentration threshold results in the ability to assess and monitor folic acid fortification programs**
  - In the US, although most women are optimally protected (77%), some who consume only mandatory fortification products remain at increased risk
- **Possible approaches that could be targeted to higher-risk populations**
  - Fortify additional dietary staples (e.g., corn masa flour was added 2017)
  - Encourage wider consumption of supplements containing folic acid
- **In Guatemala, 47% of women of reproductive age had suboptimal RBC folate concentrations because folic acid fortification was not reaching the rural, low-income, and indigenous populations**

Rosenthal J, Reeve ME, Ramirez N, Crider KS, et. al. Birth Defects Res A Clin Mol Teratol. 2016 Jul;106(7):587-95
Tinker SC, Hamner HC, Qi YP, Crider KS. Birth Defects Res A Clin Mol Teratol. 2015 Jun;103(6):517-26. Epub 2015 Apr 17

Birth Defects COUNT: What We Do

Birth Defects COUNT

Countries and Organizations United for **Neural Tube Defects Prevention**

Objective: **Significantly reduce death and lifelong disability due to neural tube defects**

Focus regions: **South-East Asia and East Africa**

Focus intervention: **Fortification with folic acid**

Fortifying Grains with Folic Acid to Prevent Neural Tube Defects: Successes and Opportunities

Scott J. Montgomery

Director, Food Fortification Initiative

U.S. Department of Health and Human Services
Centers for Disease Control and Prevention

What is Fortification?

Adding vitamins and minerals

Photo from Mühlenchemie

during the milling process

Photo by David Snyder / CDC Foundation

to produce more nutritious foods

Istockphoto

Our Niche: Wheat Flour, Maize Flour, and Rice

istockphoto

Food Fortification Initiative

Enhancing Grains for Healthier Lives

www.ffinetwork.org

Our Focus: Industrially Milled Grains

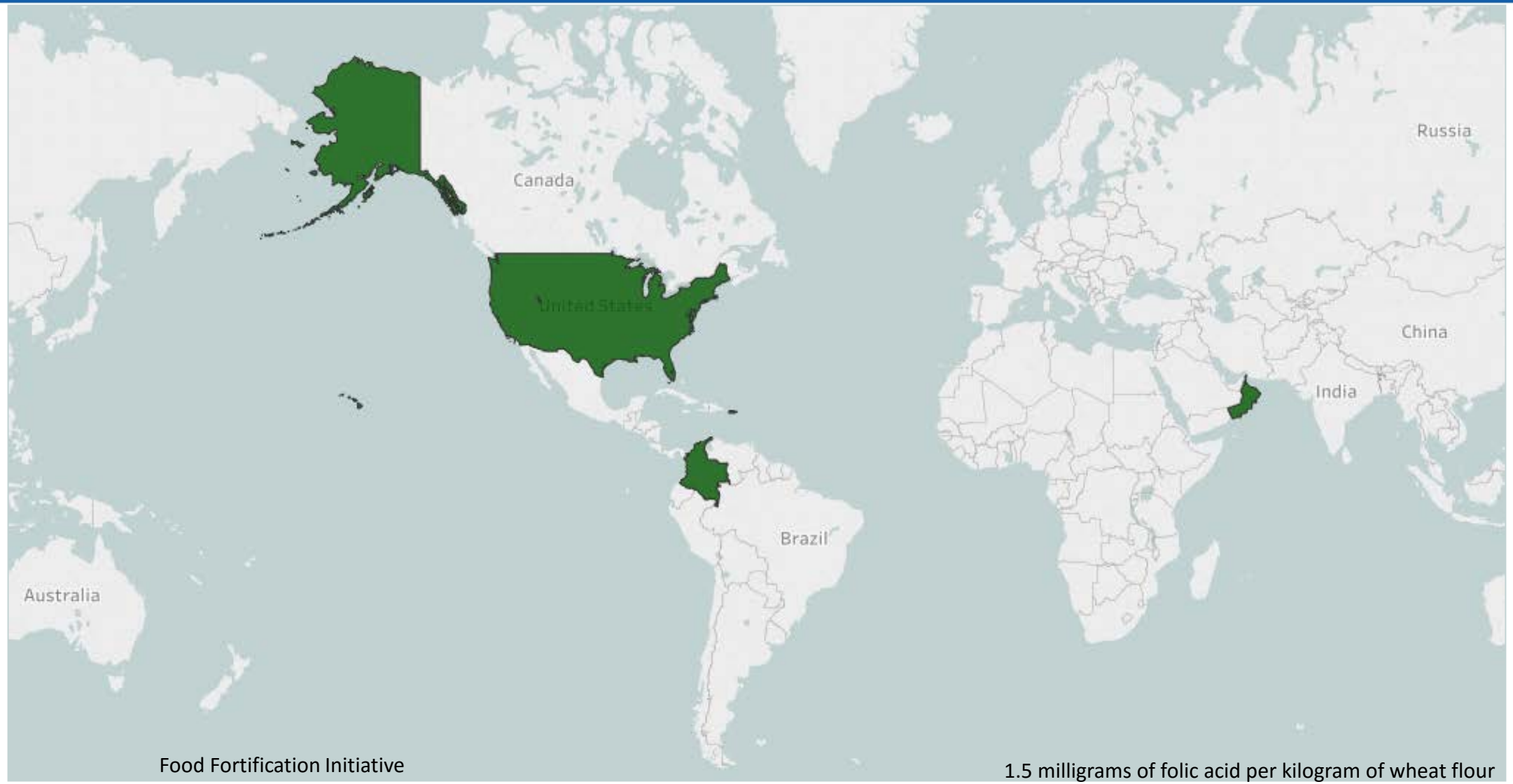
Industrial mill

Bühler photo

Village-type chakki mill

David McKee photo

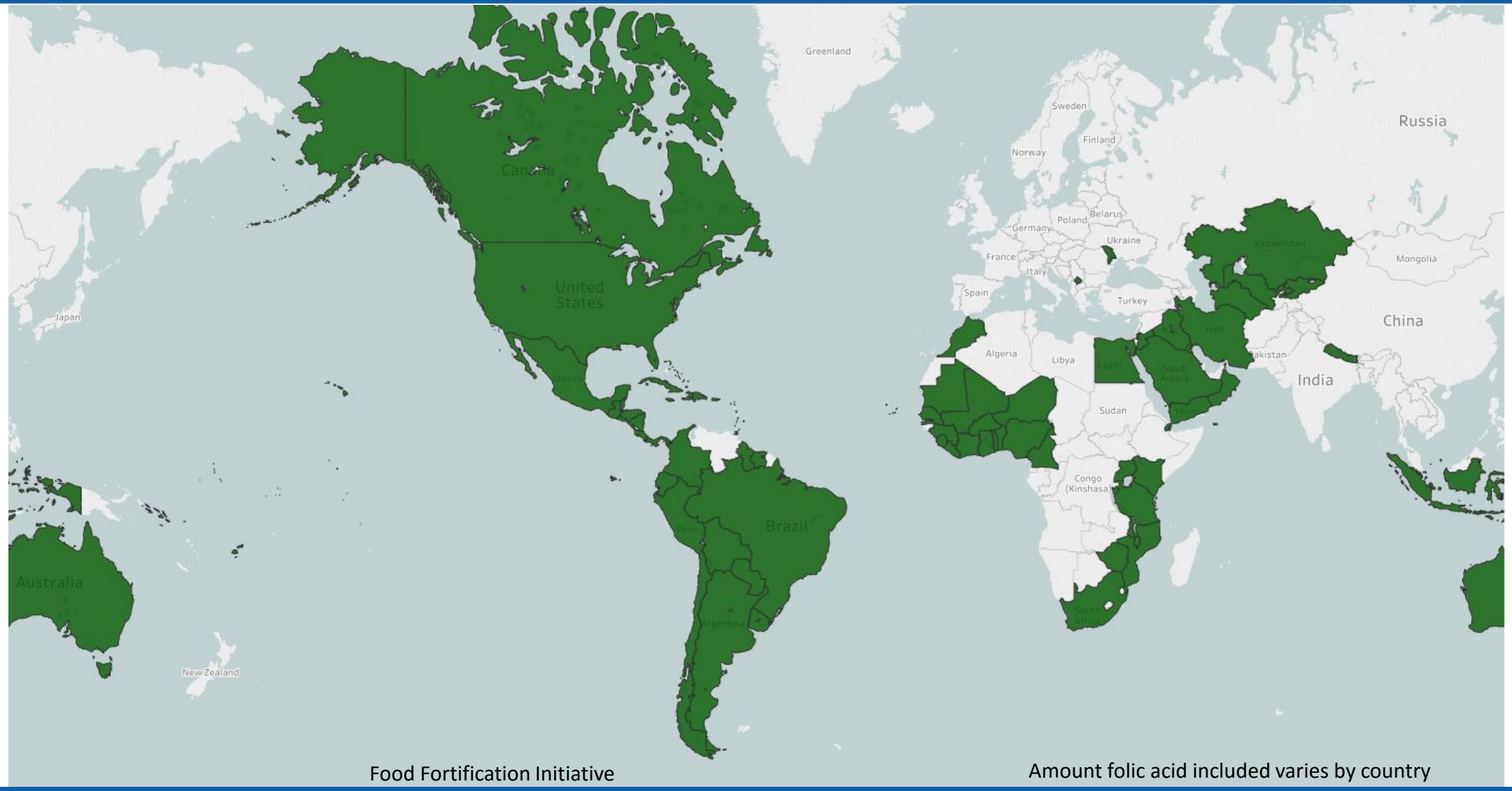
1996–1998: U.S. and Colombia Mandate Adding Folic Acid to Grains Oman Reaches National Coverage



Food Fortification Initiative

1.5 milligrams of folic acid per kilogram of wheat flour

2017: 81 Countries Require Folic Acid in Industrially Milled Wheat Flour, Maize Flour and/or Rice



Food Fortification Initiative

Amount folic acid included varies by country

Folic Acid Fortification Prevents 97 Neural Tube Defects Each Day and Counting!

Globally an estimated
35,500 birth defects
were prevented in 2015
– ***an average of 97 a day*** –
where flour was fortified
with folic acid.

Istockphoto

Arth A, Kancherla V, Pachón H, et al. Birth Defects Res A Clin Mol Teratol. 2016 Jul;106(7):520-9

Thousands More NTDs Could Be Prevented With Industrial Cereal Grain Fortification

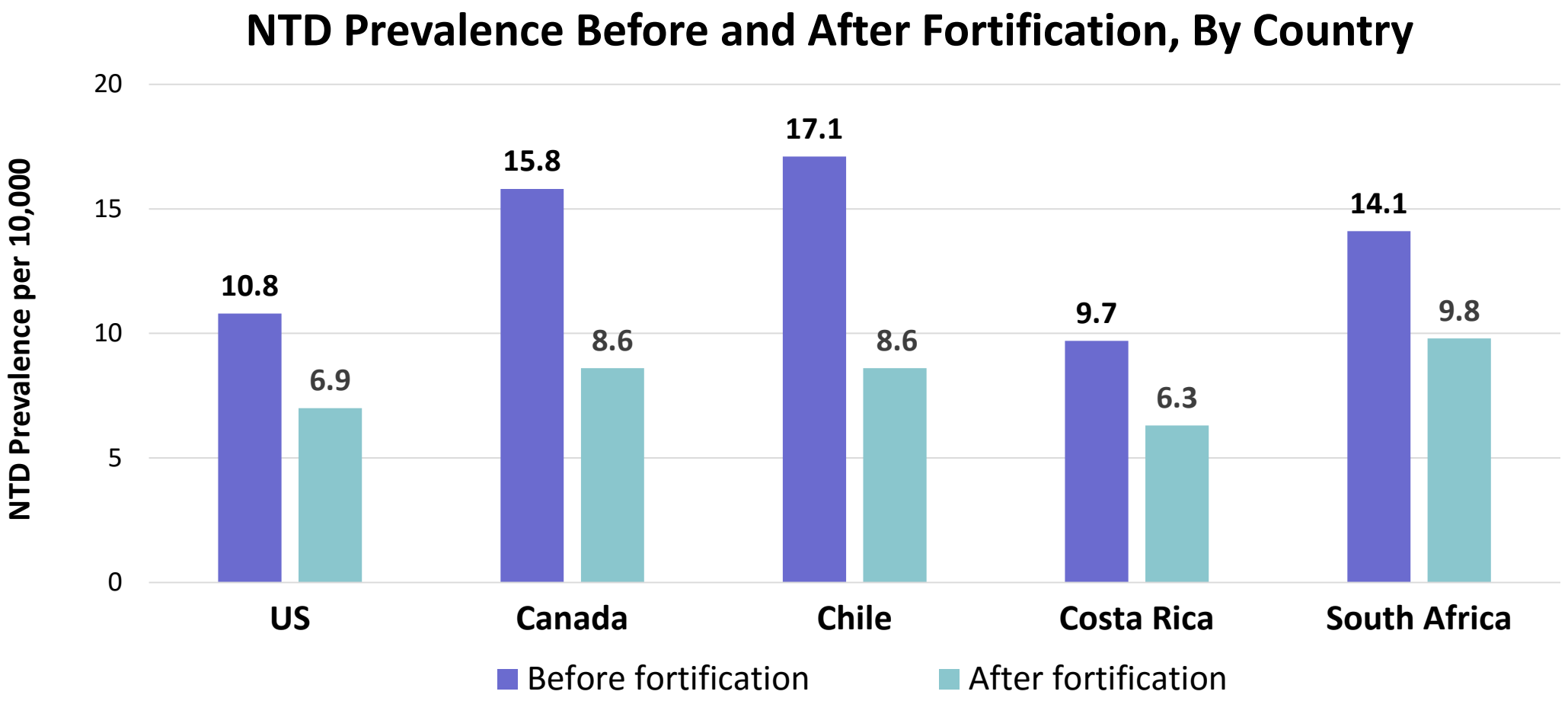
160,800 *annually*

Greatest potential impact in:

- **China**
- **India**
- **Russia**
- **Turkey**

Based on unpublished data and Arth A, Kancherla V, Pachón H, et al. Birth Defects Res A Clin Mol Teratol. 2016 Jul;106(7):520-9
Istockphoto

Fortification Led to A Drop in Neural Tube Defect Prevalence



US: CDC Grand Rounds:. MMWR. 2010;59(31):980–4
Chile: Cortes F, et. al. Amer Jnl Med Genet A. 2012 Aug;158A(8):1885–90
South Africa: Sayed AR, Birth Defects Res A Clin Mol Teratol. 2008:82(4): 211–216
Canada: De Wals, et. al. 2007. N Engl J Med357: 135–142
Costa Rica: Tacsan Chen L, Nutr Revs. 2004: 62(6):S40–S43

Cameroon Results Show Folate Levels in Women Are Increasing

Among Women in Urban Areas	2 years before fortification	1 year after fortification	Percent Increase
Plasma folate* (nmol/L)	**15**	**47**	**213%**
Plasma B12 (pmol/L)	**461**	**671**	**46%**
Plasma zinc (µg/dL)	**55**	**65**	**18%**
Ferritin (µg/L)	**37**	**47**	**27%**

Flickr Creative Commons

*Plasma/serum folate is a short-term measure and RBC folate concentration is a long-term measure of folate status and is the biomarker used for NTD risk. Correlation between plasma/serum folate concentration and RBC folate concentration is unknown.

Engle-Stone R, Nankap M, Ndjebayi AO, et. al. J Nutr. 2017 Jul;147(7):1426-1436.. Epub 2017 Jun 7
apps.who.int/iris/bitstream/10665/161988/1/9789241549042_eng.pdf

Fiji Study Demonstrates Folate and Other Nutrient Deficiencies Are Decreasing

Percent of Women Age 15–45 Deficient Before and After Flour Fortification, Fiji, N=869

Measurement	Percent Deficient Before, 2004	Percent Deficient After, 2010	Cut offs used for deficiency in women
Serum folate	**8**	**1**	Serum folate <10 nmol/L
Iron	**23**	**8**	Serum ferritin <15 mg/L
Zinc	**39**	**0**	Serum zinc <10.1 mmol/L

In addition, anemia prevalence among this group dropped from 40% to 28%.

Anemia defined as hemoglobin <12g/dL

Only 16.1% of the women had taken nutrient supplements in the six months prior to the survey
National Food and Nutrition Centre 2010 ffinetwork.org/monitor/Documents/Fiji.pdf
apps.who.int/iris/bitstream/10665/161988/1/9789241549042_eng.pdf

Fortification With Folic Acid Prevents Spina Bifida

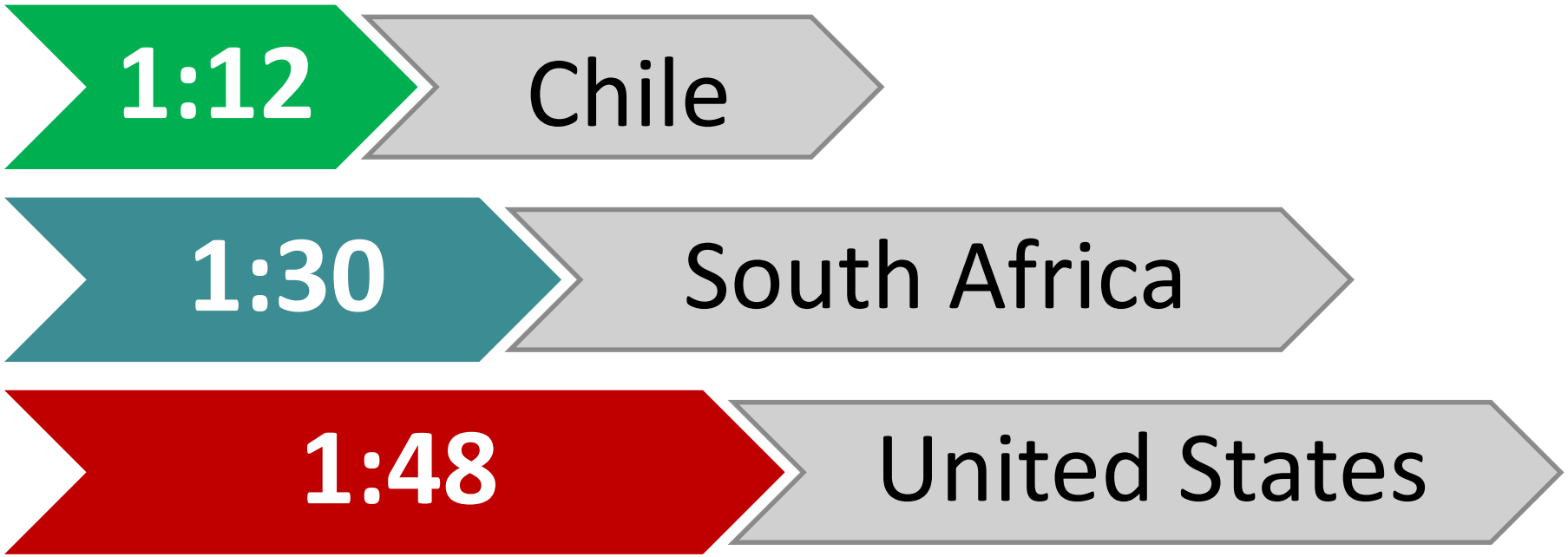
Annual Net Savings

Chile	South Africa	United States
• USD 2.3 million	• USD 5.3 million	• USD 603 million

These are conservative estimates!

Llanos A, Hertrampf E, Cortes F, et. al. Health Policy. 2007 Oct;83(2-3):295–303
Sayed AR, Bourne D, Pattinson R, et. al. Birth Defects Res A Clin Mol Teratol. 2008 Apr;82(4):211–216
Grosse SD, Berry RJ, Mick Tilford J, et. al. Am J Prev Med. 2016 May;50(5 Suppl 1):S74-80. Epub 2016 Jan 11

Return on Investment from Preventing Spina Bifida



Llanos A, Hertrampf E, Cortes F, et. al. Health Policy. 2007 Oct;83(2-3):295-303
Sayed AR, Bourne D, Pattinson R, et. al. Birth Defects Res A Clin Mol Teratol. 2008 Apr;82(4):211–216
Grosse SD, Berry RJ, Mick Tilford J, et. al. Am J Prev Med. 2016 May;50(5 Suppl 1):S74-80. Epub 2016 Jan 11

Fortification Opportunities in Industrially Milled Grains

	Wheat Flour *million metric tons*	Maize Flour *million metric tons*	Rice *million metric tons*
Available for human consumption	355	90	377
Industrially milled	250	26	171
Industrially milled and fortified	85	14	1
Percent industrially milled and fortified	**34%**	**57%**	**0.7%**

Food and Agriculture Organization of the United Nations (FAO) for 2013.

FFI calculations. Food Fortification Initiative. Say Hello to a Fortified Future. 2016 Year in Review. FFI: Atlanta, USA 2017. ffinetwork.org/about/stay_informed/publications/documents/FFI2016Review.pdf

Fortification Opportunities With The Most Potential Impact

- Industrial milling is available
- At least 75 grams of grain available per person per day
- Fortifying with folic acid is not mandatory for all commonly consumed grains

Summary

200,000 NTDs could be prevented annually through grain fortification

- **Enduring value**
- **Minuscule costs**
- **Enormous benefits**

istockphoto

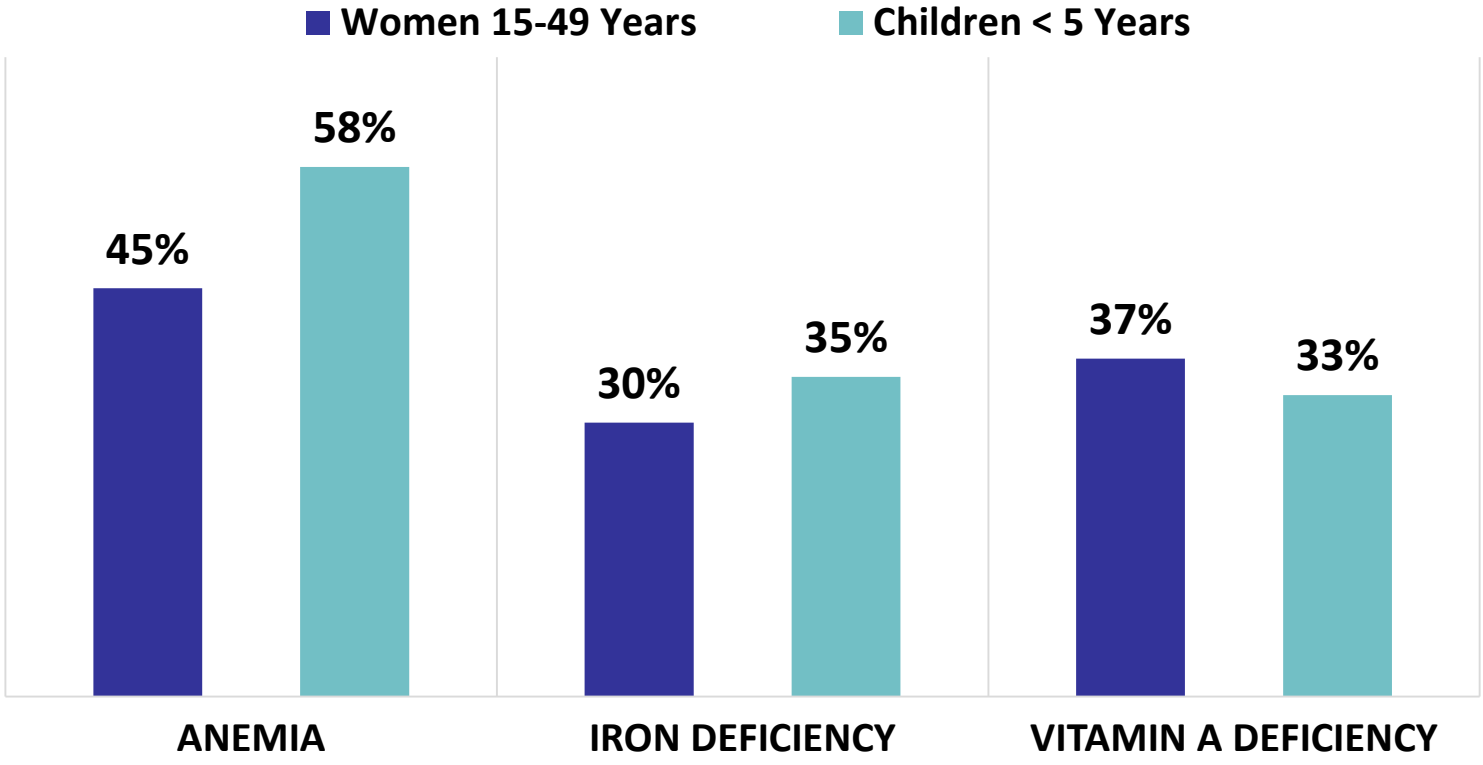
Maize Fortification with Small- and Medium-scale Processors in Tanzania

Erin Smith, MPH
Country Director, Tanzania,
Helen Keller International

U.S. Department of Health and Human Services
Centers for Disease Control and Prevention

Micronutrient Status Has Improved in Tanzania But Malnutrition Remains

Percent of Women and Children with Certain Health Characteristics of Micronutrient Malnutrition, Tanzania, TDHS 2015



- **34% of children are stunted**
- **Under Five Mortality (U5MR): 81/1,000**
- **Infant Mortality: 51/1,000**

National Bureau of Statistics (NBS) [Tanzania] and ICF Macro. 2011. *Micronutrients: Results of the 2010 Tanzania Demographic and Health Survey*. Dar es Salaam, Tanzania: NBS and ICF Macro.

NTD Prevalence in Tanzania Is Extremely High

- **Review of NTD prevalence in neonates in the largest referral hospital in Tanzania in 2002**
- **NTD rate of 30.2 per 10,000 live births**
  - 4,840 new cases per year
- **High level of stigma against children born with NTDs or disability**
  - Poor access to services results in a large number of cases are not seen by medical personnel

Child with encephalocele

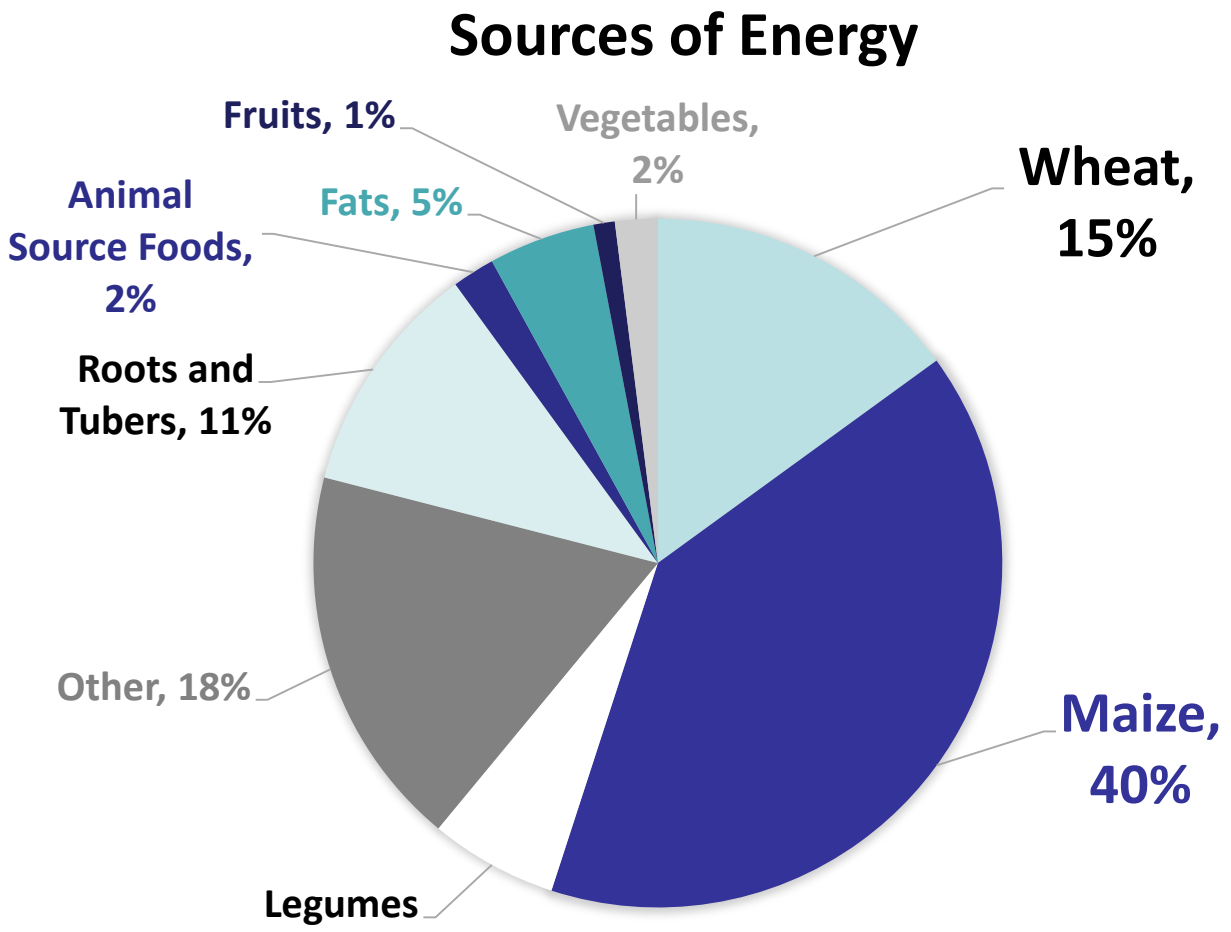
Kinasha AD, Manji K. Eur J Pediatr Surg. 2002 Dec;12 Suppl 1:S38-9.

History of Fortification in Tanzania

- **National Food Fortification Standards and Regulations requires large-scale industries to fortify**
  - Law passed in March 2011
- **Industrial wheat and maize flour producers**
  - Add iron EDTA, zinc oxide, folate, Vitamin E, and vitamin B12
- **Vegetable oil producers to add**
  - Add Vitamin A
- **Salt producers**
  - Add potassium iodate

EDTA: ethylenediaminetetraacetate

Wheat vs. Maize Consumption Among Poor



- **Average diet contains 2x more maize than wheat AND maize less likely to be fortified than wheat flour**
  - Only 36% consume wheat but 59% of wheat flour is fortified
  - Over 89% consume maize but only 3% of maize is fortified

Survey disaggregated data by poor and non-poor using the multi-dimensional poverty index methodology

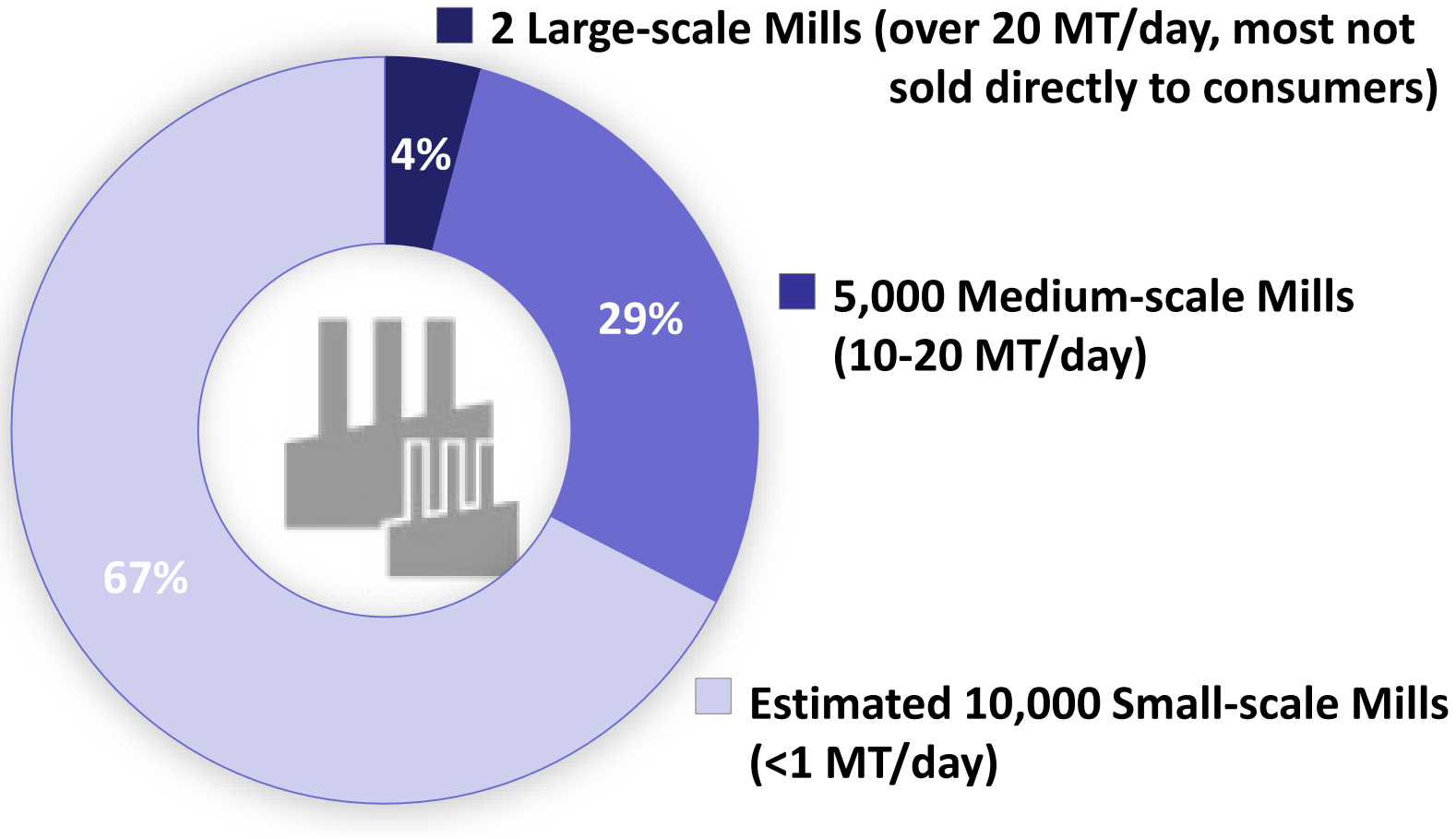
FACT Survey, Tanzania, GAIN 2015. nbs.go.tz/nbs/takwimu/references/FACTSURVEY2015/FACTSurvey2015-Slides.pdf

Unpublished data, Fill the Nutrient Gap Survey Tanzania 2017, World Food Programme

Maize Production in Tanzania Is Fractured

Number of Mills and Percentage of Maize Milled

- 96% of maize is produced by small- and medium-scale mills
- 6,892,480 MT each year



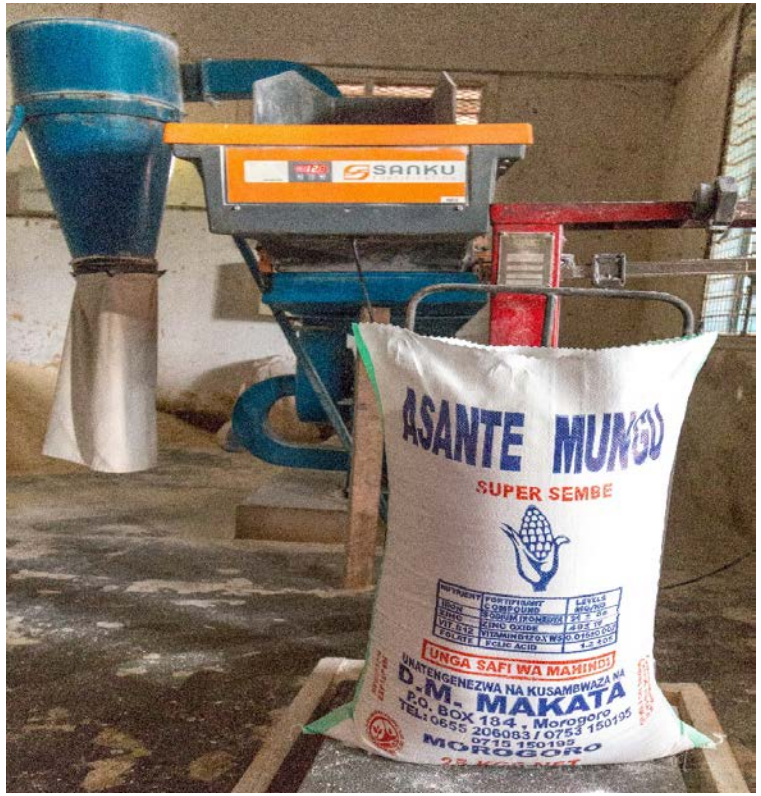
MT: Metric tons

Many Challenges in Small- and Medium-scale Folic Acid Fortification

- **For millers, no motivation to fortify**
  - Small and medium millers not included in Fortification Law
  - Difficult to access to affordable technology and micronutrient mix
  - **Lack of consumer demand and awareness = no market for product**
- **Poor and rural residents don't purchase maize flour**
  - Maize grown at home is often ground at small local mills

Community Intervention to Target Small- and Medium-scale Mills

- How could we work with 10,000 millers to fortify maize?
- What about millers' compliance?
- Would it be cost effective?
- How could we reach the population who needed it most?
- How could we know we were having an impact?

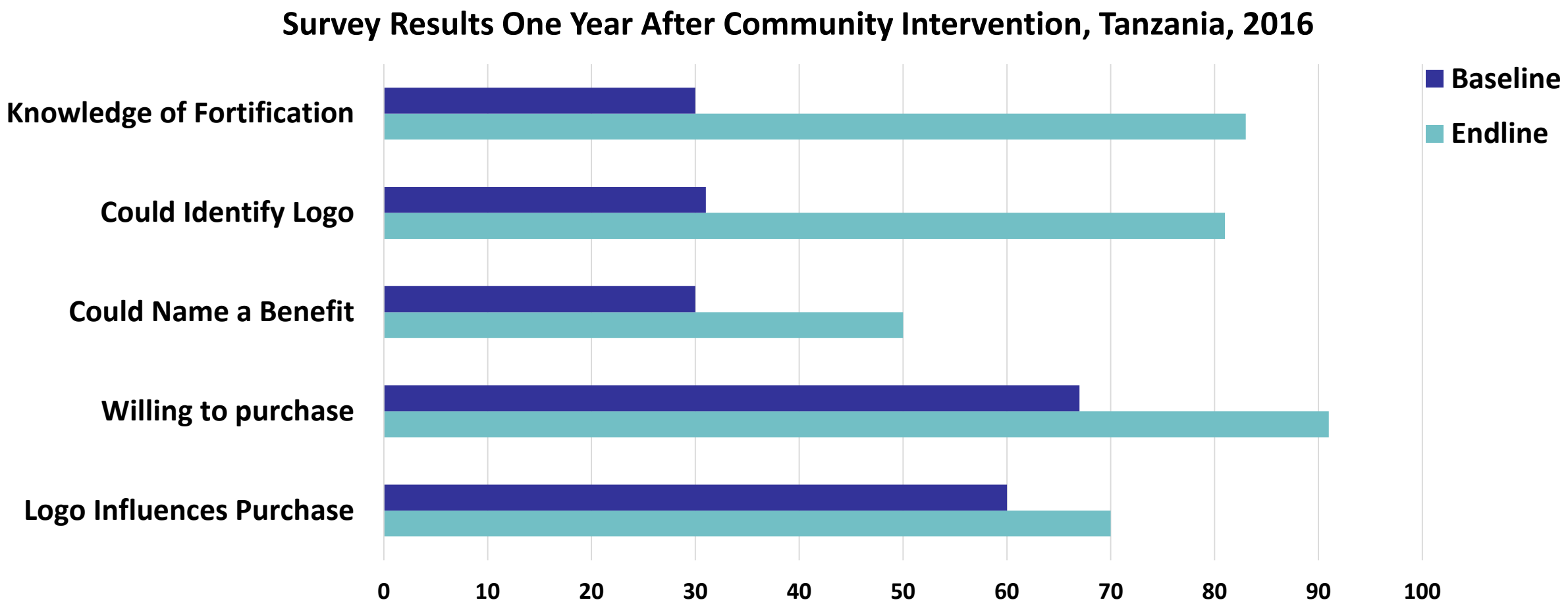


Components of a Successful Fortification Program

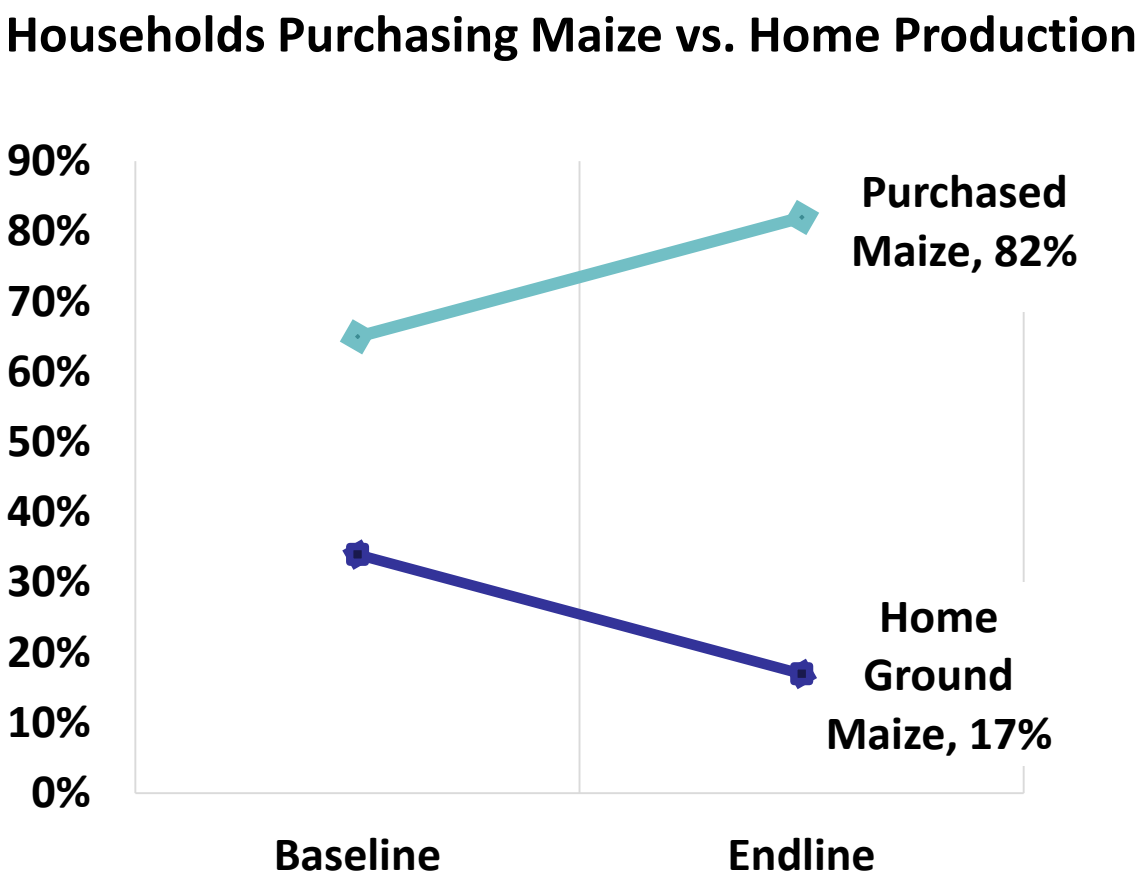
Measuring Progress After The First Year

- **Baseline and endline assessments were conducted one year apart in January of 2016 and 2017 in three districts in Morogoro**
  - Population-representative sample: 400 Households (200 Urban/200 Rural) P:0.05
- **Study Objectives: Assess changes in**
  - Acceptability
  - Purchasing and consumption patterns
  - Household access

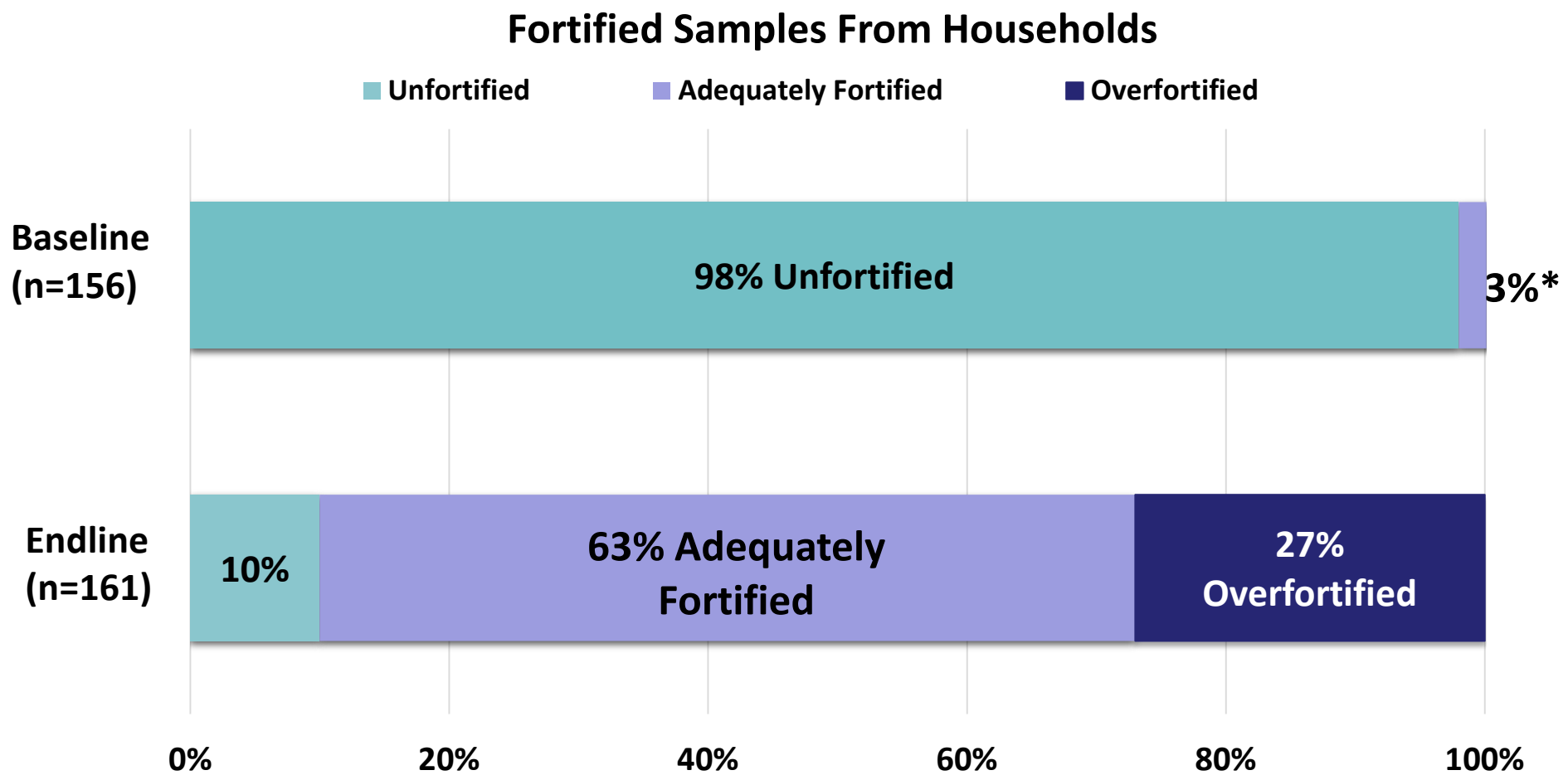
Changes in Acceptability of Fortified Products



Purchasing Habits Changed in Just One Year



Household Consumption Changed in Just One Year



*Does not add to 100% due to rounding

Increased Access for Poor Families

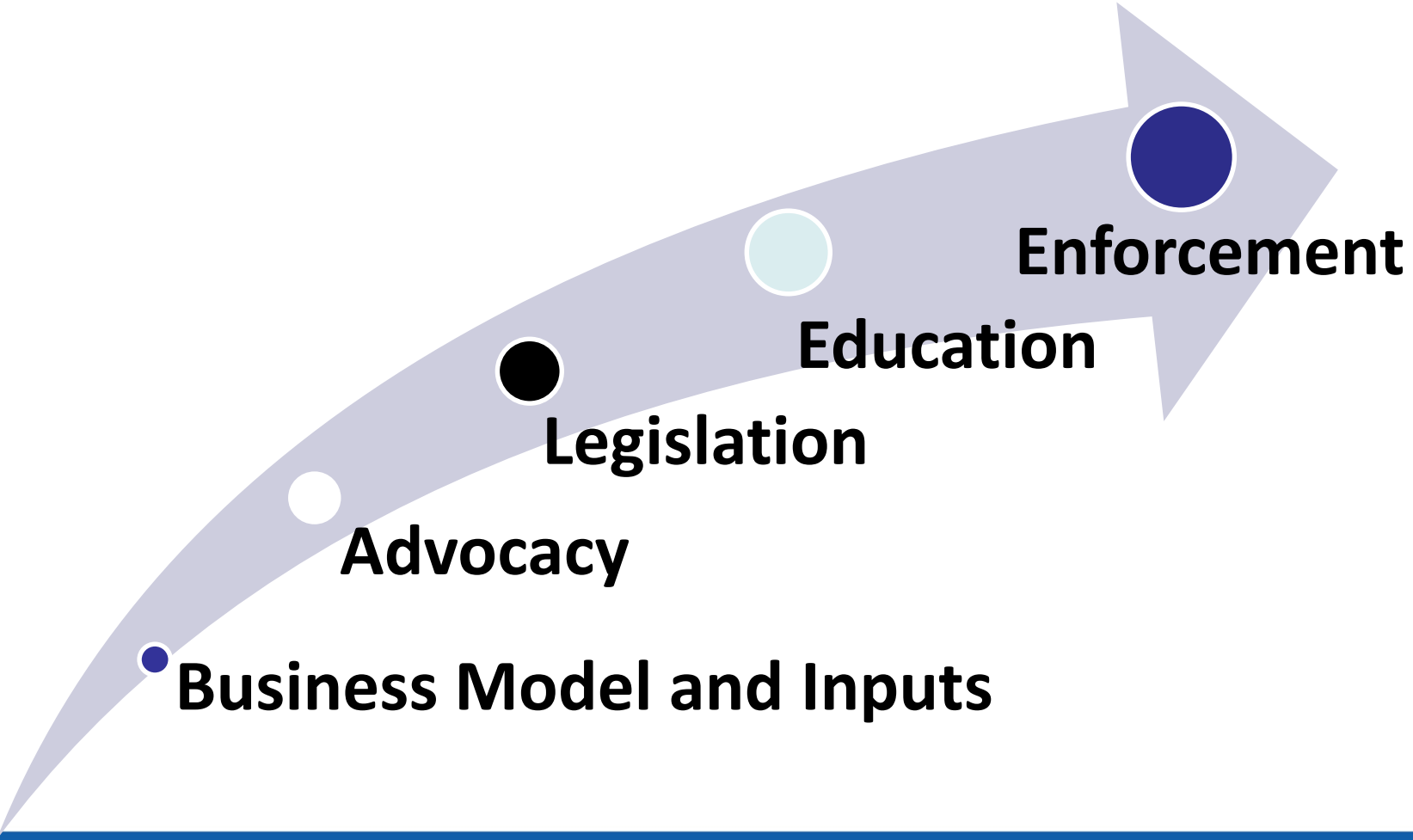
- 81% of poor households regularly purchasing packaged maize
- 94% of flour sampled in poor households fortified
- 72% of poor households accessing fortified flour

Legislative Steps Taken To Sustain Fortification

- **By-law passed in Morogoro region in September 2017**
- **Adds sustainability to efforts**
- **Requires Small Scale Maize producers to add**
  - Iron EDTA, zinc oxide, folate, Vitamin E, and vitamin B12

EDTA: ethylenediaminetetraacetate

Successful Fortification Leads to Healthier People



Improved Market Demand

Improved Access to Product

Higher Quality Production

Safer Food Products

Healthier Population

Asante Sana

Birth Defects Surveillance and Prevention in South-East Asia: Lessons Learnt and Way Forward

Dr Neena Raina

Coordinator, Health through the Life Course

WHO-SEARO

U.S. Department of Health and Human Services
Centers for Disease Control and Prevention

Wheat Flour Fortification in India – A New Beginning

- India is estimated to hold 1/3 of the world's NTDs
- Many staple foods are not centrally milled (e.g., chakki mills)
- Food Safety and Standards Authority of India (FSSAI) set initial fortification standards for micronutrients too low
  - Folic acid level was below level to prevent NTDs
- In 2016, WHO-SEARO, CDC, FFI, and other partners led a successful effort to have FSSAI amend standards to align with global WHO standards

FFI: Food Fortification Initiative

FSSAI File no. 11/03/Reg/Fortification http://ffrc.fssai.gov.in/fortification/data/FinalSummitReportwebsite.pdf

Building A Birth Defects Surveillance System

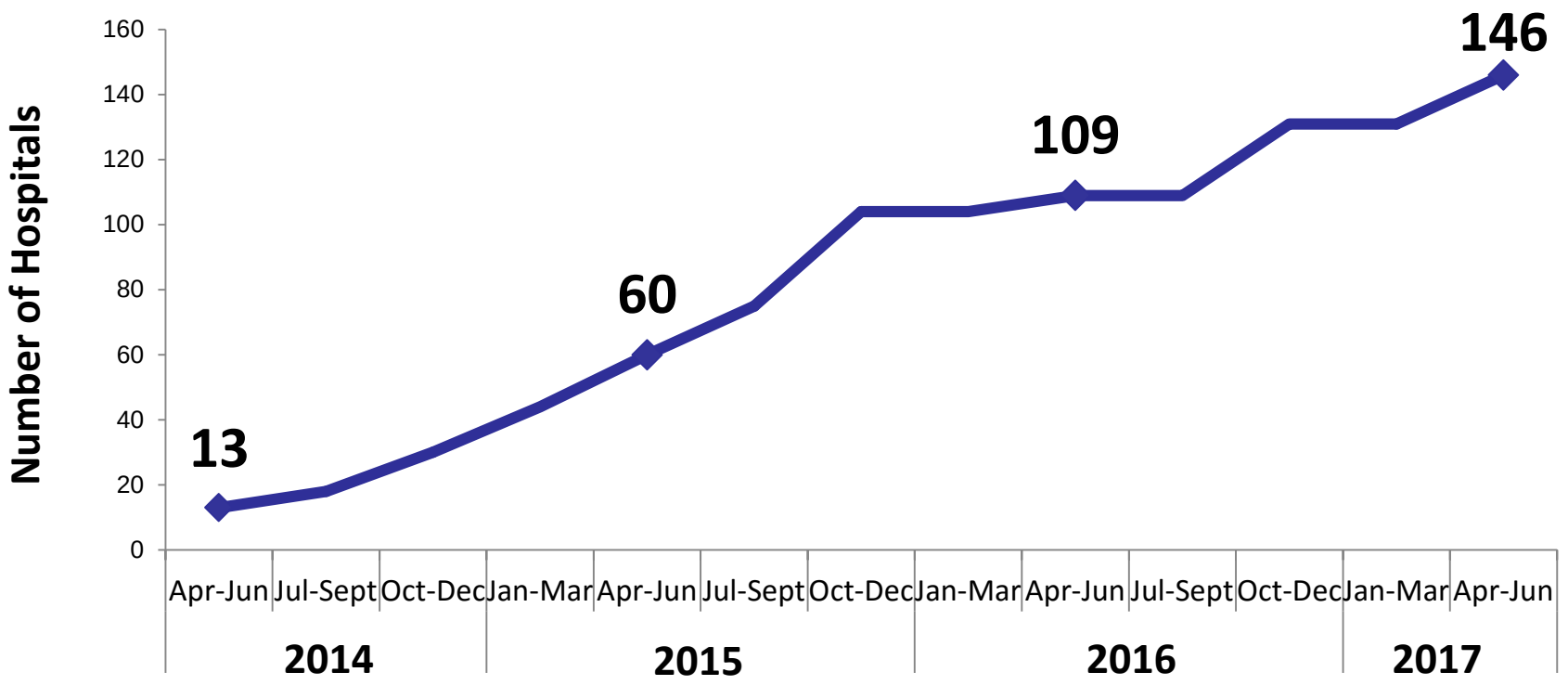
- **To understand the impact of fortification and to demonstrate reduction in the number of NTDs, we needed data**
- **WHO-SEARO and CDC collaborated to develop a reliable birth defects surveillance system**
  - Regional Strategic Framework
  - National strategies and plans
- **In 2014, launched SEAR-NBBD Database**
  - Define the magnitude and distribution of birth defects in SEAR

who.int/mediacentre/factsheets/fs178/en/

Progressive Increase In Reporting Hospitals

World Health Organization
Regional Office for South-East Asia
SEAR-NBBD

Number of Hospitals Reporting to SEAR-NBBD Hospital-based Birth Defects Surveillance and Database, 2014–2017, (146 online/108 offline)



7 countries online

Bangladesh
Bhutan
India
Nepal
Maldives
Myanmar
Thailand

3 countries offline

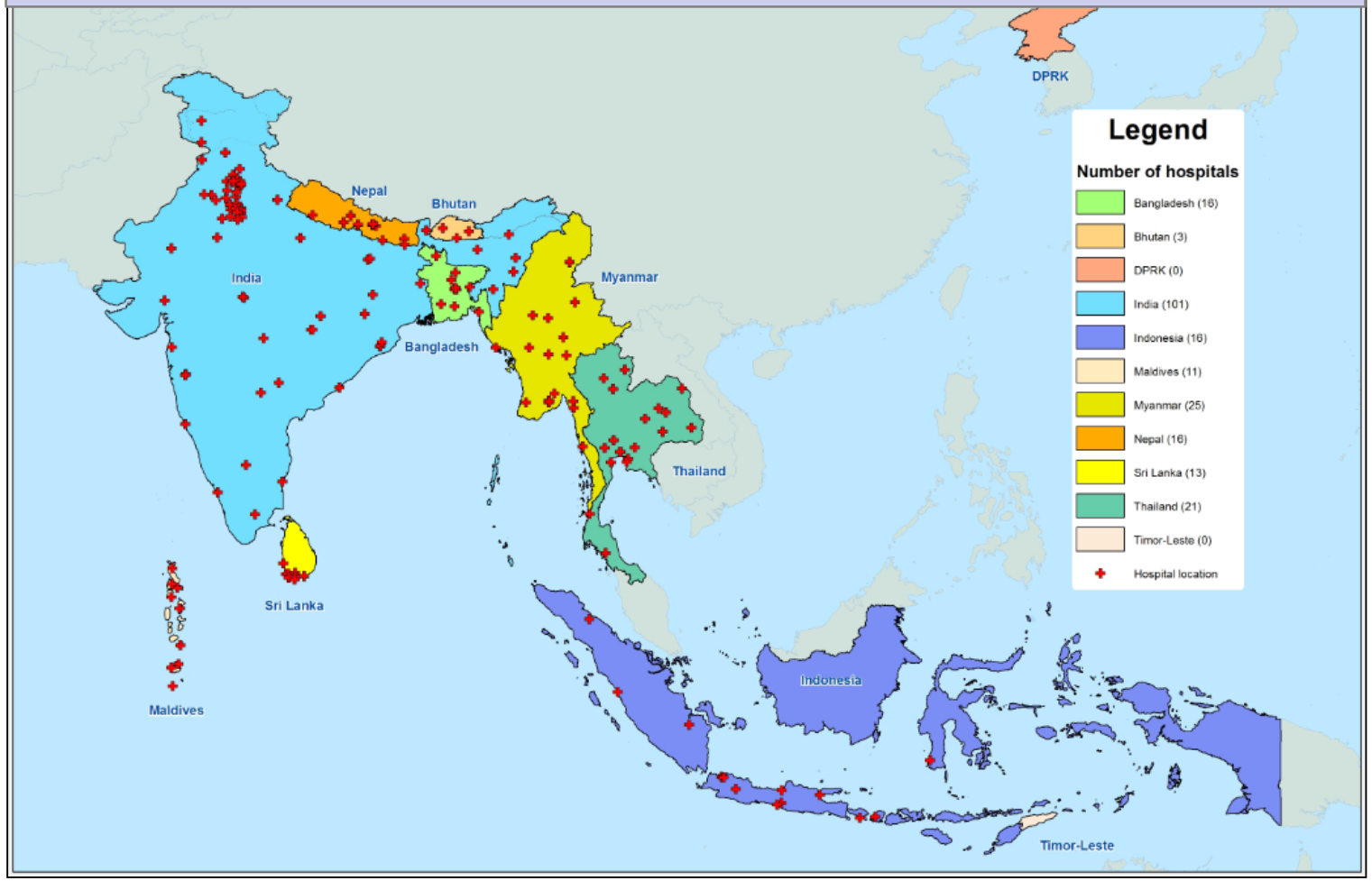
Indonesia
Sri Lanka
Timor Leste

SEAR-NBBD Surveillance Data, July 2014–June 2017

Hospital-based Newborn and Birth Defects (NBBD) Surveillance & Database

World Health Organization
Regional Office for South-East Asia
SEAR-NBBD

Hospital-Based Surveillance across 10 WHO-SEAR Countries, 2014–2017



- **Standardized forms available online and through mobile app**
- **Training of data entry operators and other health professionals**
- **Verification and quality monitoring of data**
  - Troubleshooting and periodic monitoring

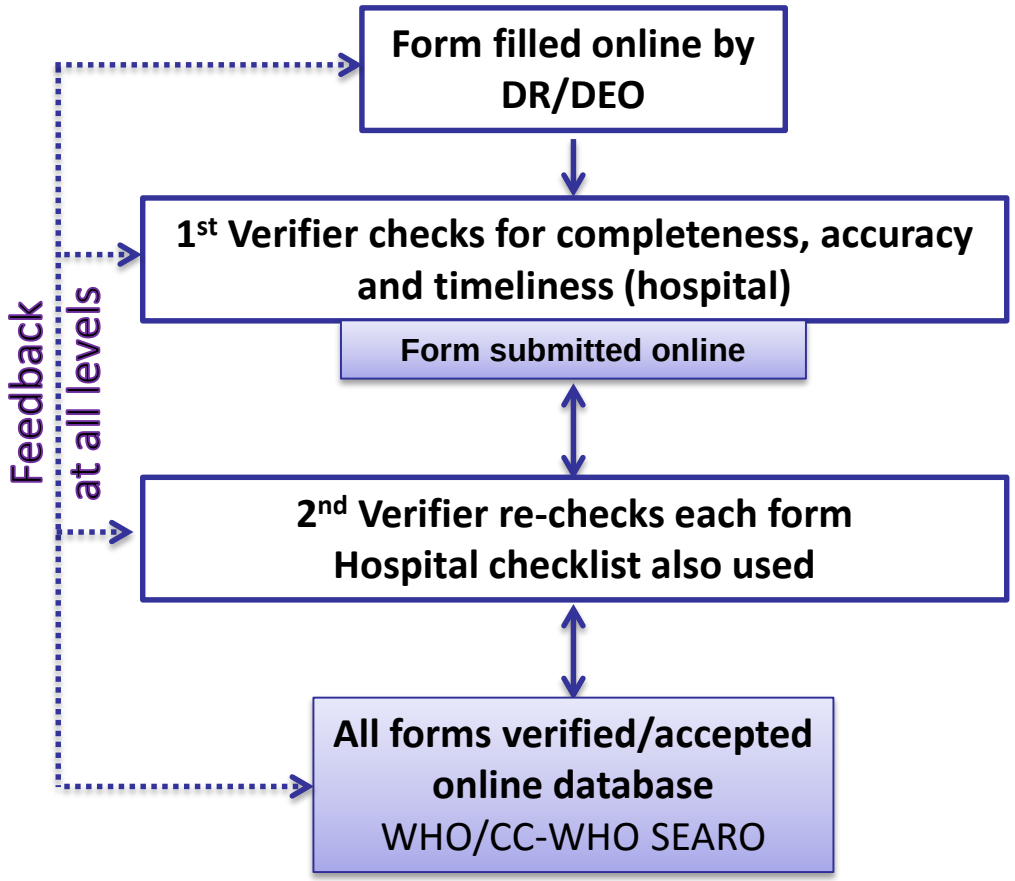
✚ **Reporting hospital**

SEAR-NBBD Surveillance data July 2014- June 2017

NBBD Is a Unique Surveillance System

World Health Organization
Regional Office for South-East Asia
SEAR-NBBD

1. **Hospital-based surveillance**
   - Fetus or baby delivered in the hospital
   - Birth defects identified at birth or until 7 days of life or until discharge
   - All live births and stillbirths born with a birth defect
   - Initial focus is on major structural birth defects but all BD included now
   - Monthly denominators are submitted

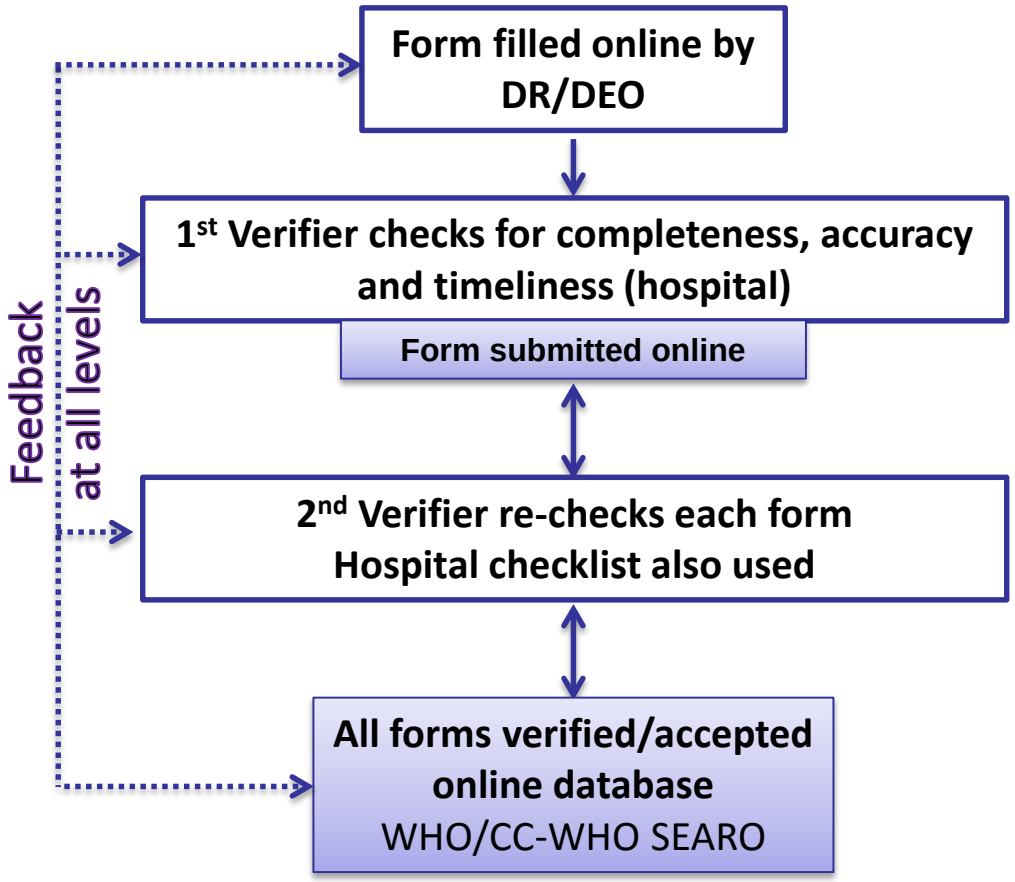


SEAR-NBBD Surveillance Data, July 2014–June 2017

NBBD Is a Unique Surveillance System

World Health Organization
Regional Office for South-East Asia
SEAR-NBBD

2. **Quality assurance of surveillance at all levels**
   - All birth defects forms once submitted online are verified for completeness, accuracy and timeliness
   - Feedback loop has been established to maintain data quality
3. **Involvement of Ministry of Health (MoH) in every country**
   - Government hospitals
   - Periodic follow-up easier due to MoH
   - Sustainable

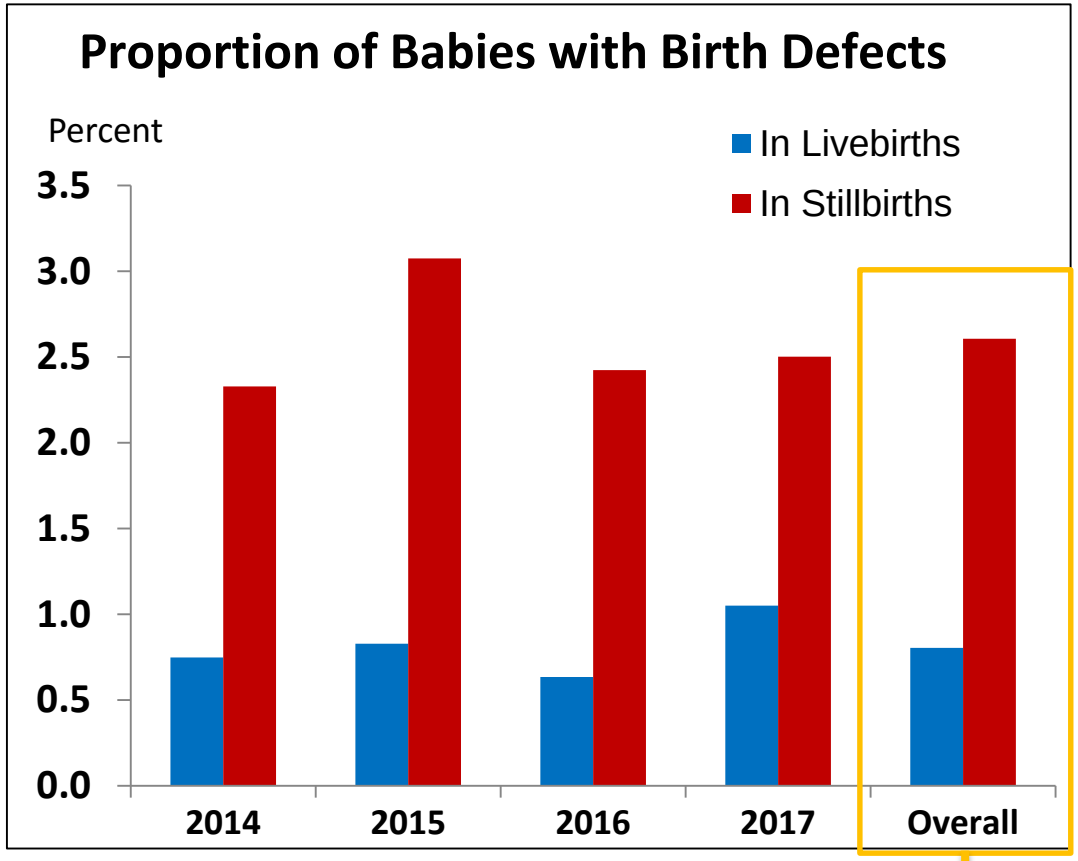


SEAR-NBBD Surveillance Data, July 2014–June 2017

Birth Defects Surveillance Highlights (2014-2017)

World Health Organization
Regional Office for South-East Asia
SEAR-NBBD

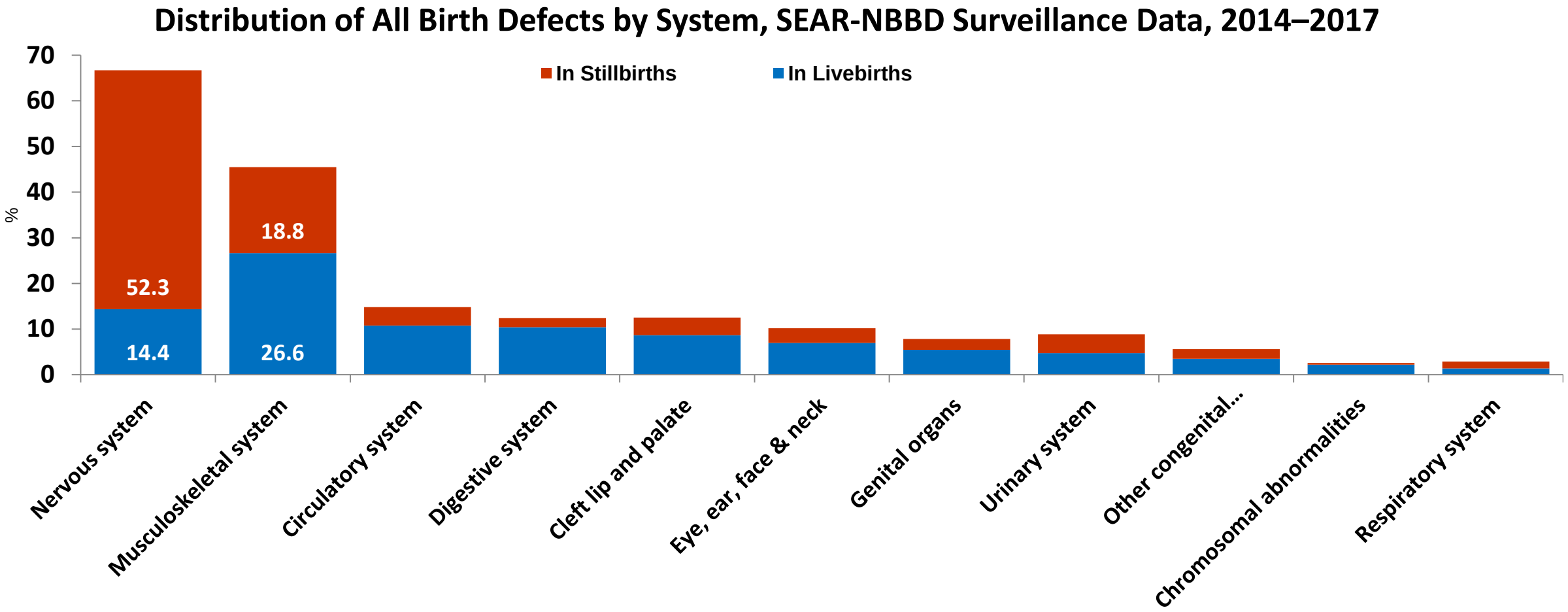
Total Births Reported	**1.60 million**
• Total Livebirths	1.56 million
• Total Stillbirths	45,800
Total Birth Defects Reported	**Over 16,500**
Total Babies with Birth Defects	**~14,000 (0.89%)**
• Birth Defects in Livebirths (overall)	~12,500 (0.80%)
• Birth Defects in Stillbirths (overall)	~1,200 (2.61%)



Data are from the 146 hospitals in 7 countries that reported online to NBBD between 2014–2017 and does not reflect of the overall prevalence or proportion of birth defects in these countries. Data represent only the information collected on BD from participating hospitals from the NBBD network that often focusses on visible birth defects. However, with better training and more interest at the hospital level, all BDs started being reported hence the spike in 2015. Total babies with Birth defects (LBs and SBs) have been rounded off. SEAR-NBBD Surveillance Data, July 2014–June 2017.

Distribution of Birth Defects by System
Nervous System Most Commonly Reported

World Health Organization
Regional Office for South-East Asia
SEAR-NBBD



Neural tube defects are classified into the Nervous System
SEAR-NBBD Surveillance Data, July 2014–June 2017

Distribution of Birth Defects by System
Nervous System Most Commonly Reported

World Health Organization
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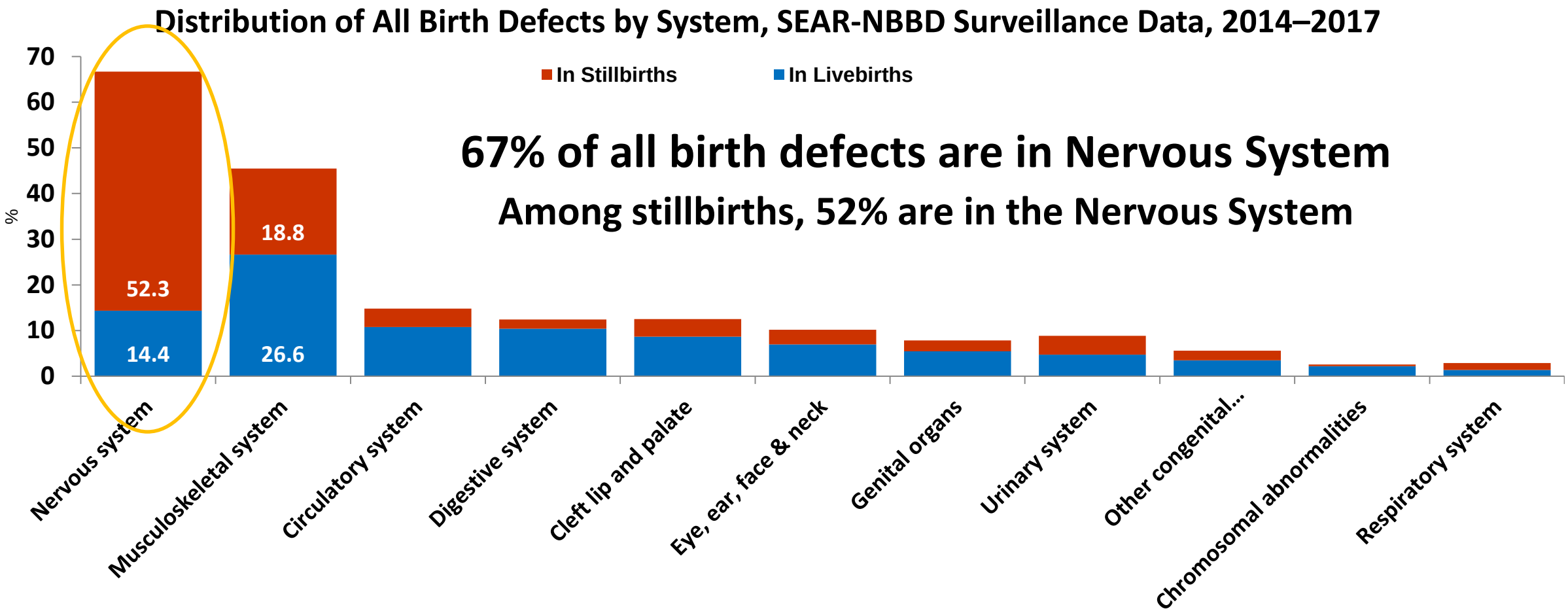
SEAR-NBBD



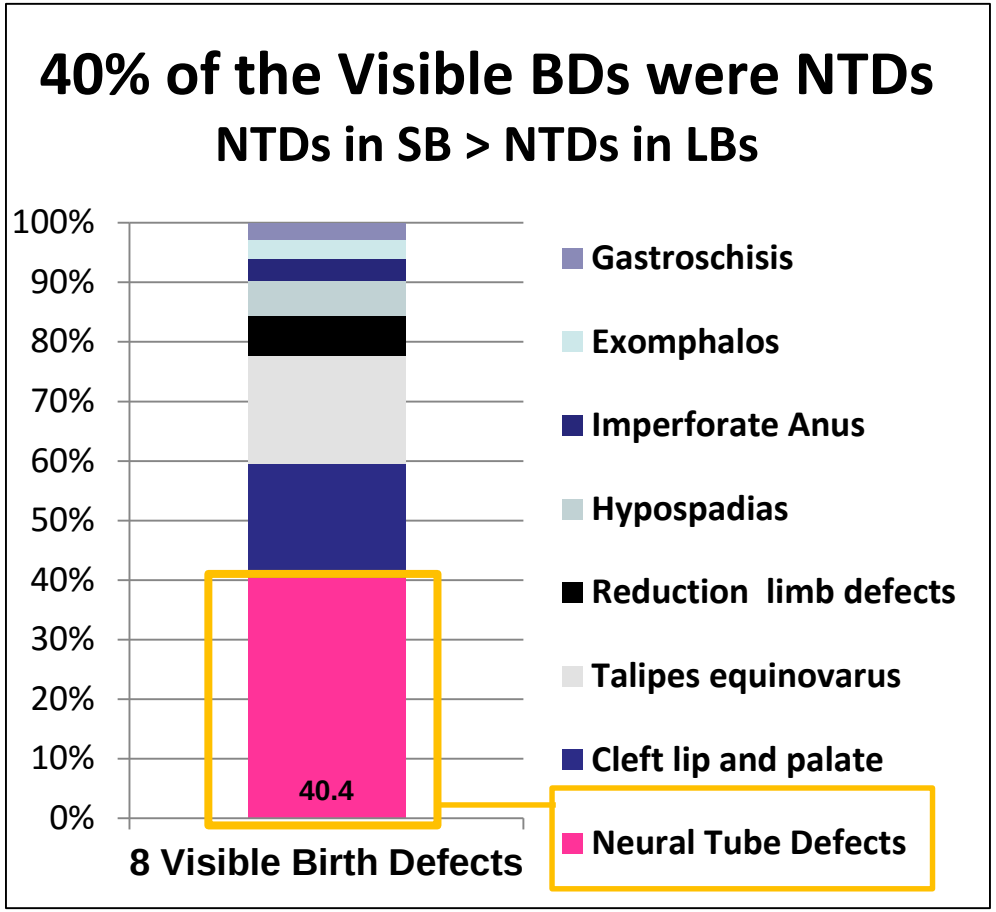
67% of all birth defects are in Nervous System

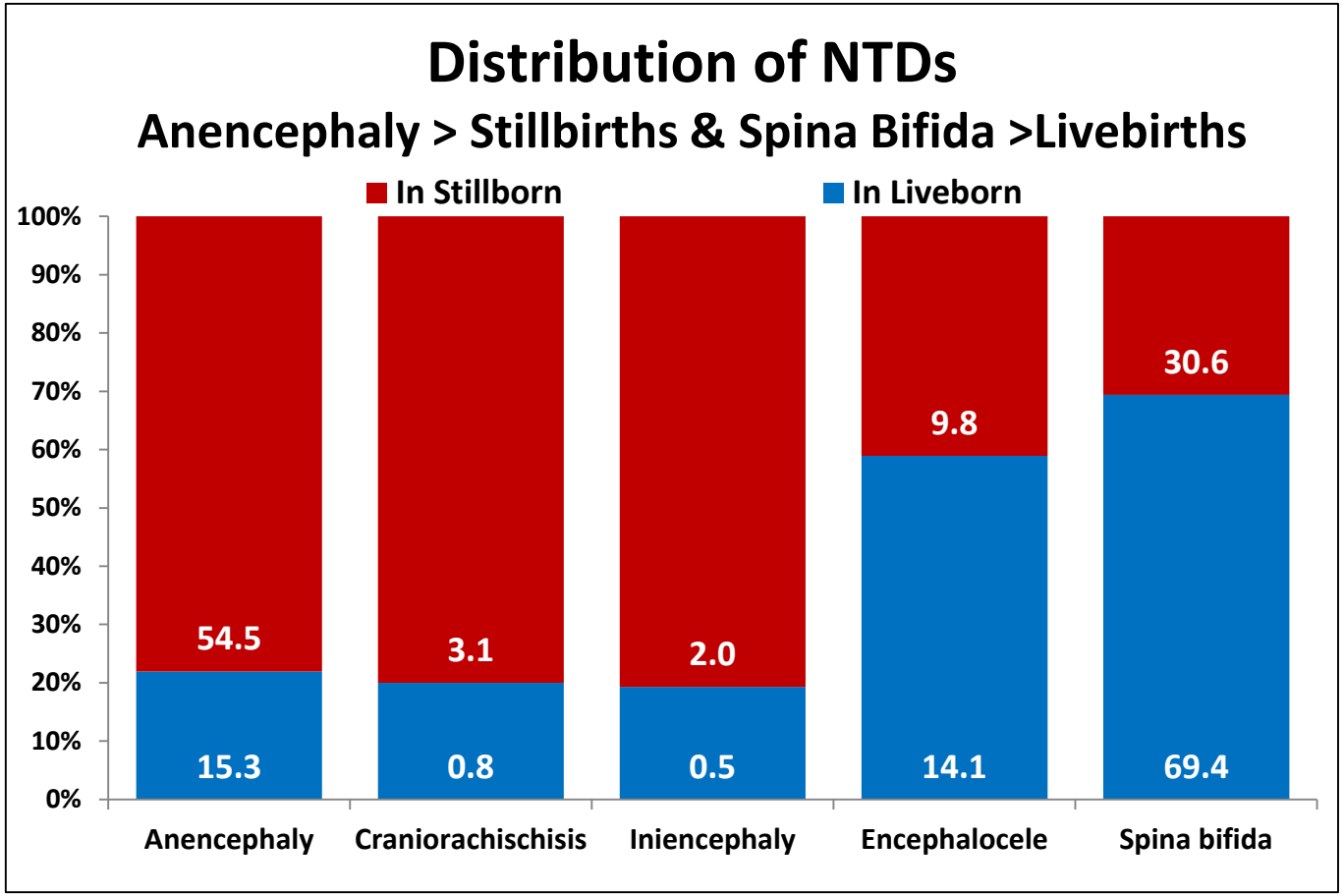
Among stillbirths, 52% are in the Nervous System

Neural tube defects are classified into the Nervous System
SEAR-NBBD Surveillance Data, July 2014–June 2017

Distribution of Visible Birth Defects and NTDs

World Health Organization
Regional Office for South-East Asia
SEAR-NBBD





SEAR-NBBD Surveillance Data, July 2014–June 2017

Distribution of Visible Birth Defects and NTDs

World Health Organization
Regional Office for South-East Asia
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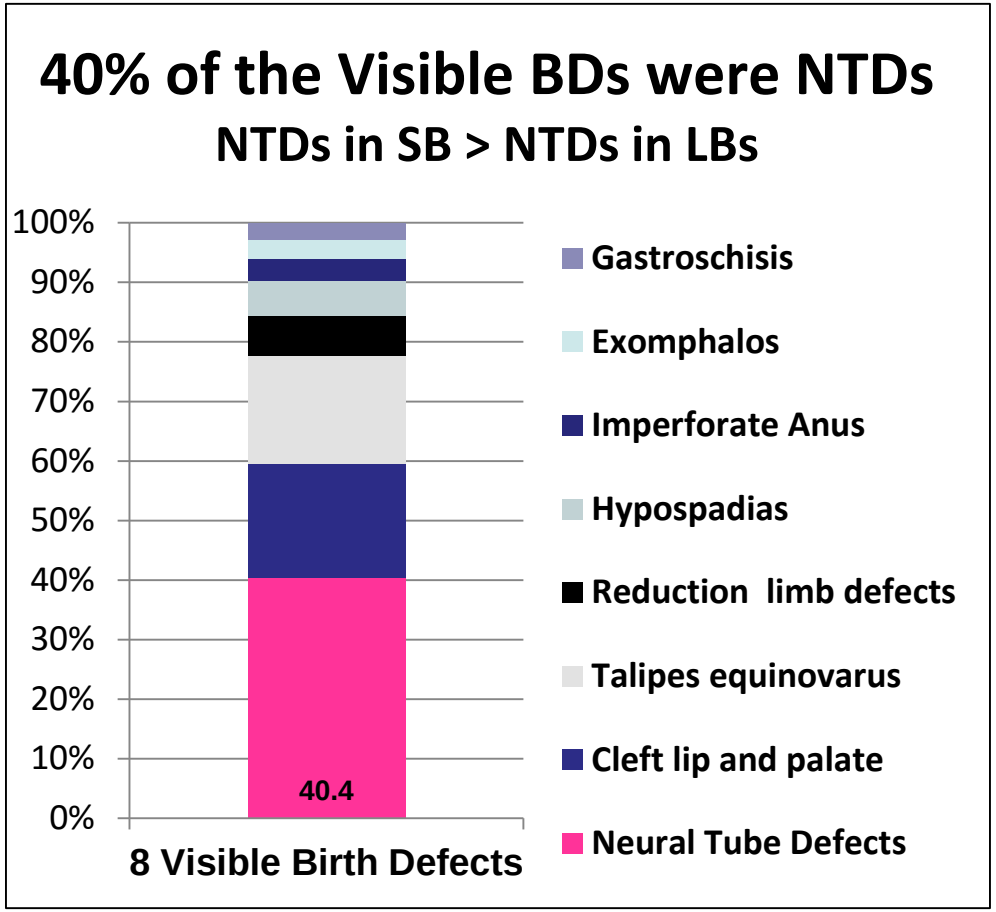
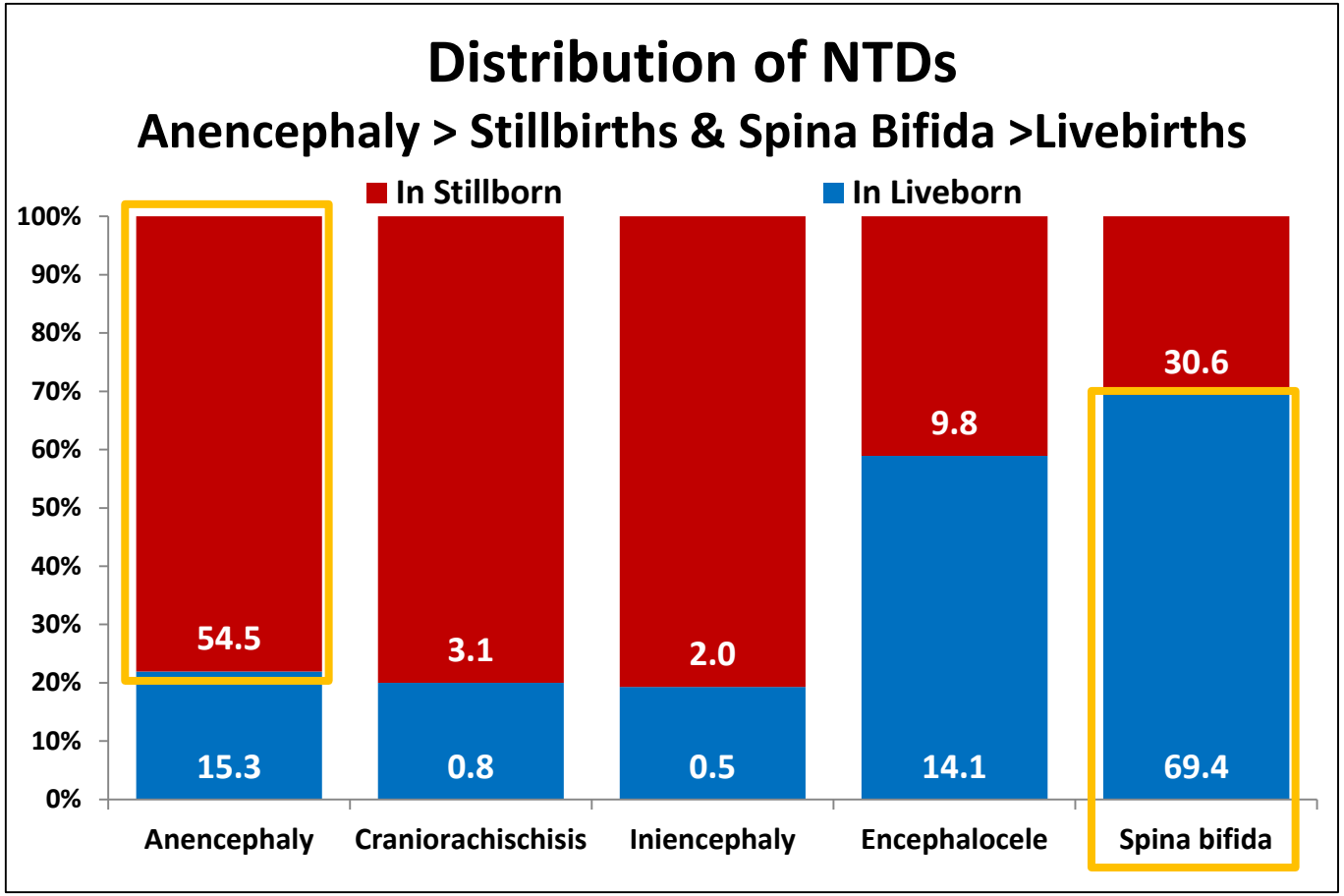


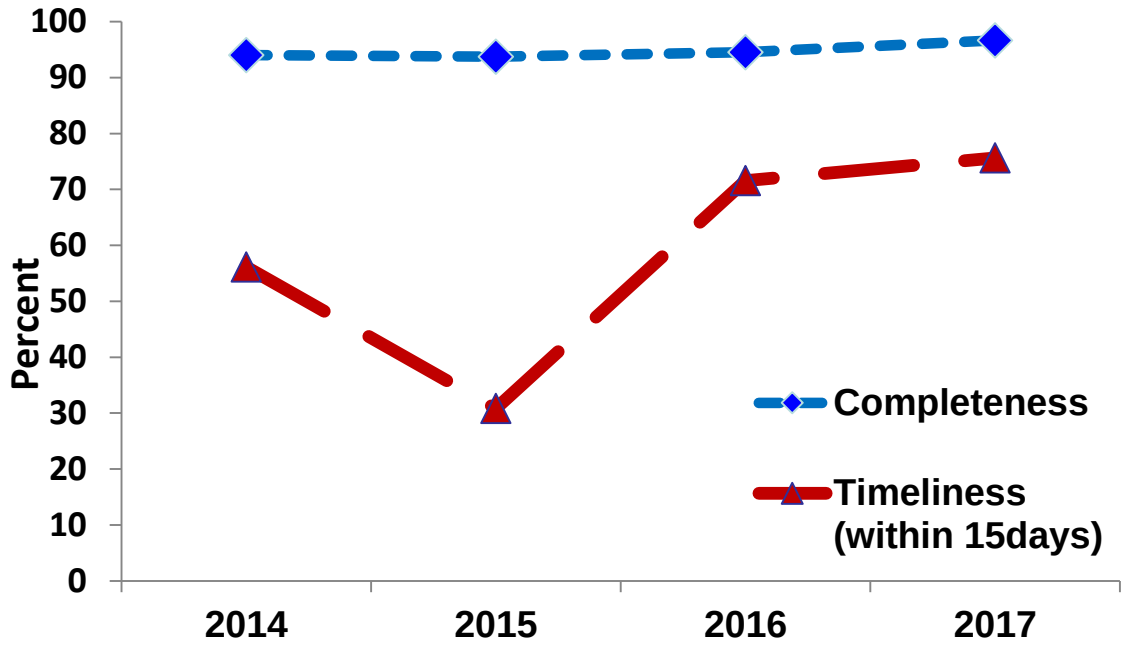


SEAR-NBBD Surveillance Data, July 2014–June 2017

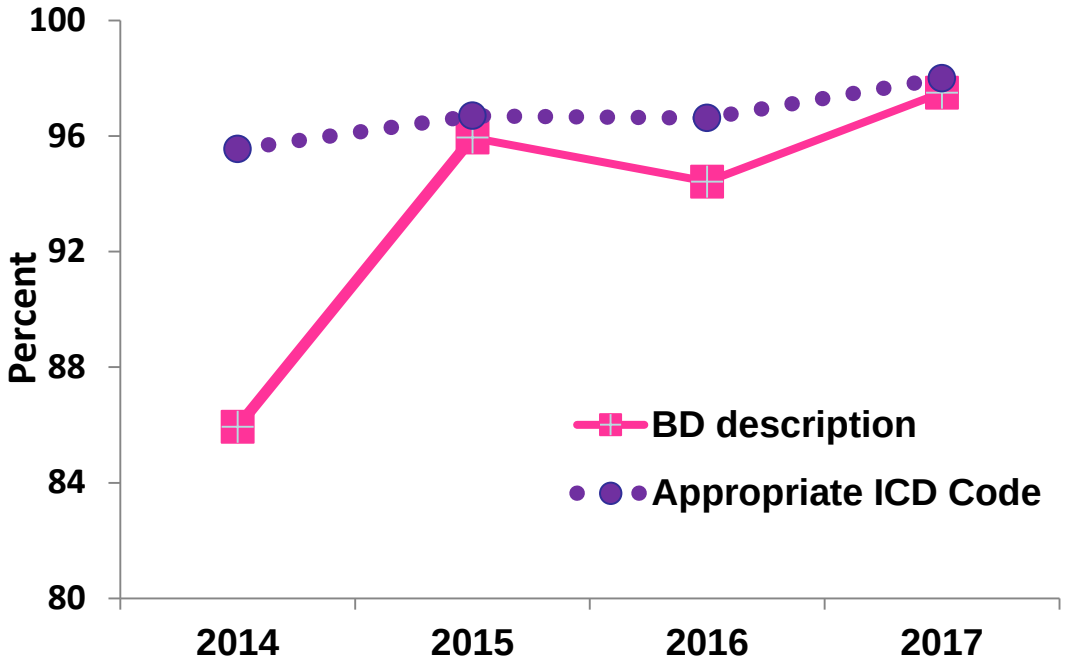
Current Focus: Further Improving Data Quality and Evaluating Efforts

World Health Organization
Regional Office for South-East Asia
SEAR-NBBD

Completeness of form improved Timeliness still challenging



BD description & ICD coding has improved considerably



SEAR-NBBD Surveillance Data, July 2014–June 2017

Stillbirth Pilot and Previable Study, India, 2014–2017

World Health Organization
Regional Office for South-East Asia
SEAR-NBBD

- **NTDs in stillbirths four times higher than livebirths in NBBD**
- **Stillbirth pilot had similar findings**
  - Every third case of stillbirth had an NTD
- **Lessons led to stillbirths surveillance expansion under NBBD**

2014
SB Pilot in India
--10 Hospitals Chandigarh network

2015
Pilot expanded
-10 Hospitals added in Delhi network

2016
Trainings held to strengthen capacity

2017
India – 55 Hospitals
Bhutan – 3 Hospitals

SEAR-NBBD Surveillance Data, July 2014–June 2017

Key Lessons Learnt from Implementing NBBD Surveillance and Database

World Health Organization
Regional Office for South-East Asia
SEAR-NBBD

- **Stakeholder engagement is key**
- **Focal points with clearly defined roles for birth defects surveillance important for smooth operations**
- **Periodic refreshers and trainings needed for good data**
- **Focus on data quality and use by analysis and interpretation**
- **Hospital network can be leveraged**
  - e.g., sharing guidelines and monitoring HCM during Zika outbreak
- **Country-level MoH commitment is needed for sustainability**

Microcephaly picture source: CDC

HCM: Head circumference measurements
MoH: Ministry of Health

Evidence for Action : Demonstration Project in Haryana, India

- **Aim -- assess the feasibility, sustainability, and health impact of fortifying wheat flour with iron, folic acid, vitamin B12 using India's existing open market and government systems**

Phase 1

Birth Defect Surveillance	Baseline household survey, Lab capacity and biomarker tests, Supply chain analysis, community needs assessment

Phase 2

Birth defect Surveillance	Fortification implementation

Phase 3

Birth defect Surveillance	Impact Evaluation

And the journey of NTD prevention continues…

Prevent Birth Defects
Improve Newborn Survival -
Ensure Quality of Life and Dignity

Thank You

In Collaboration with WHO-SEARO and CDC, USA

Acknowledging collaboration

CDC USA: National Center on Birth Defects and Developmental Disabilities
Ministries of Health
Network Hospitals
WHOCC at AIIMS New Delhi
CAH unit at WHO-SEARO

Global Prevention of Neural Tube Defects

October 17, 2017

U.S. Department of Health and Human Services
Centers for Disease Control and Prevention