WHO International Collaborative Research Project on Child Development and Prenatal Risk Factors with a Focus on FASD

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World Health Organization

Guiding principles of the Global strategy to reduce the harmful use of alcohol (WHO, 2010)

…

"Protection of populations at high risk of alcohol-attributable harm and those exposed to the effects of harmful drinking by others should be an integral part of policies addressing the harmful use of alcohol."

…

alcohol

Global strategy to reduce the harmful use of alcohol

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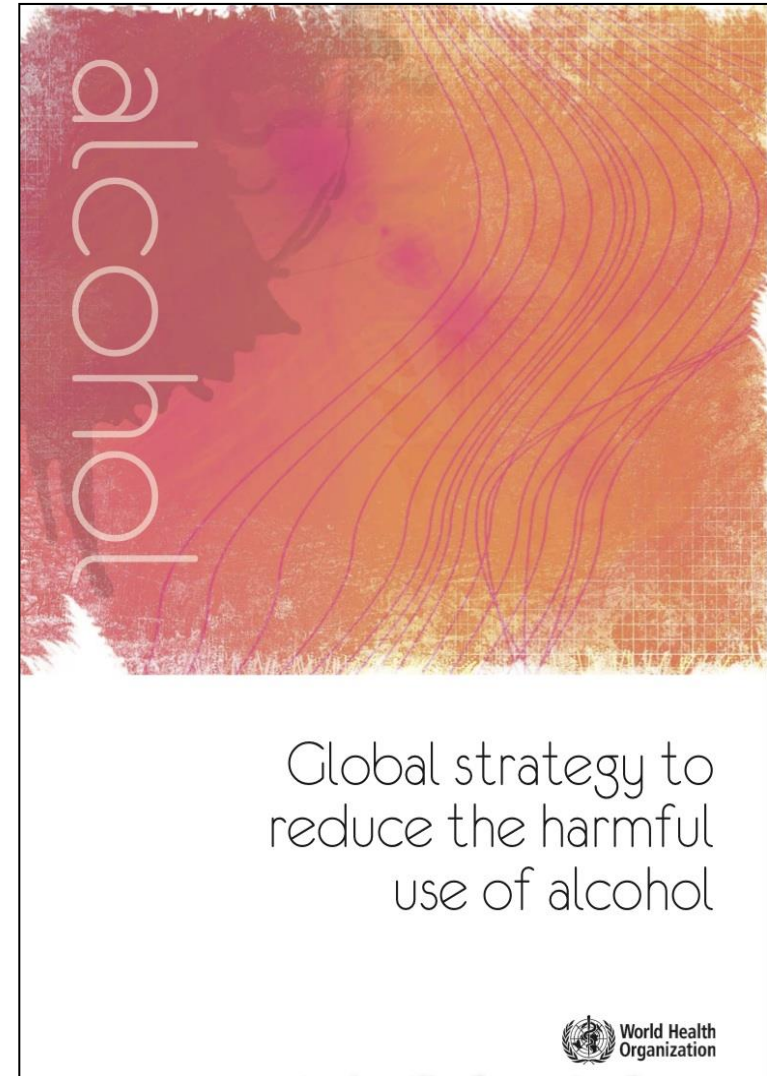
# WHO Global Research Initiative on Alcohol, Health and Development

- WHO International Collaborative Research Project on Child Development and Prenatal Risk Factors with a Focus on Fetal Alcohol Spectrum Disorders
  - In collaboration with CAMH (Canada) and NIAAA (USA)

- WHO International Collaborative Research Project on the Harm to Others From Drinking
  - In collaboration with ThaiHealth Foundation (Thailand)

- WHO International Collaborative Research Project on Alcohol and Infectious Diseases (HIV, TB)

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Global strategy to reduce the harmful use of alcohol (WHO, 2010)

Propose the following measure for implementation at nation level:

- (b) supporting initiatives for screening and brief interventions for hazardous and harmful drinking at primary health care and other settings; such initiatives should include early identification and management of harmful drinking among pregnant women and women of child-bearing age;

- (c) improving capacity for prevention of, identification of, and interventions for individuals and families living with fetal alcohol syndrome…; ...

alcohol

Global strategy to reduce the harmful use of alcohol

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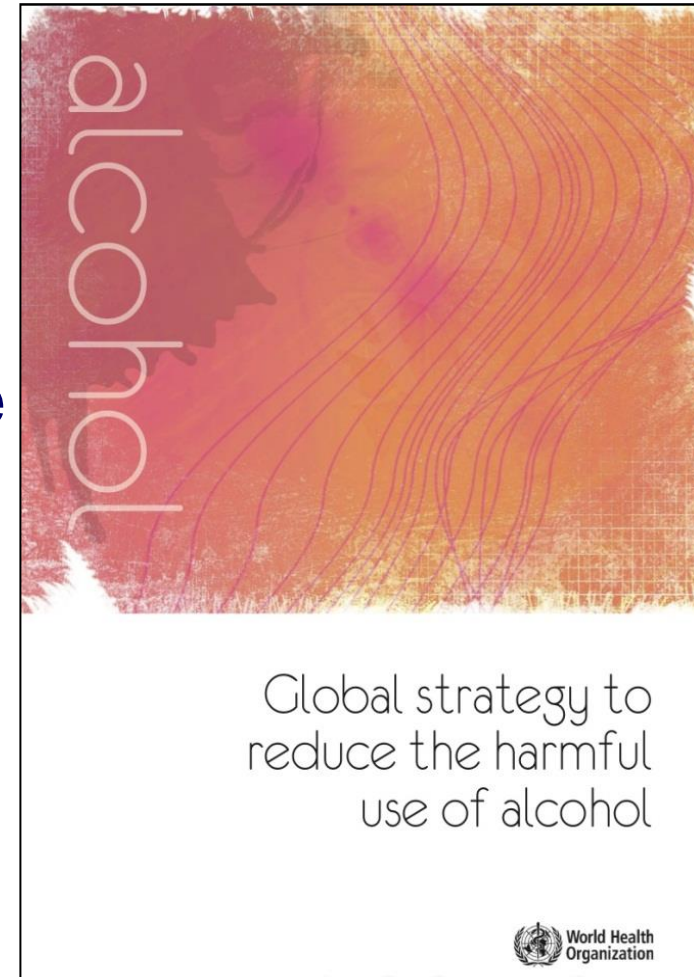
Prevalence vary depending on METHOD of SURVEILLANCE

	Birth prevalence per 1,000 live births
OVERALL (all studies)	0.5
METHODS	
Active case ascertainment	1.7
Clinic-based	0.7
Passive	0.4

The higher prevalence rates were reported in the ACA studies followed by clinic-based & passive methods

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Drinking in Women of Childbearing Age

- Among women of childbearing age, many drink alcohol; a surprising number binge drink;
- Among pregnant women: many consume alcohol; a surprising number binge drink
- Alcohol freely crosses the placenta and the embryo/fetus is exposed to the same levels as the mother.
- 60% of women who drink during pregnancy do not recognize their pregnancy until after the 4th week
- The adverse effects of prenatal alcohol exposure can occur before a woman knows she is pregnant
- About half of pregnancies are unplanned

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Global prevalence (%) of alcohol use (any amount) during pregnancy among the general population in 2012

Source: Popova et al, 2017

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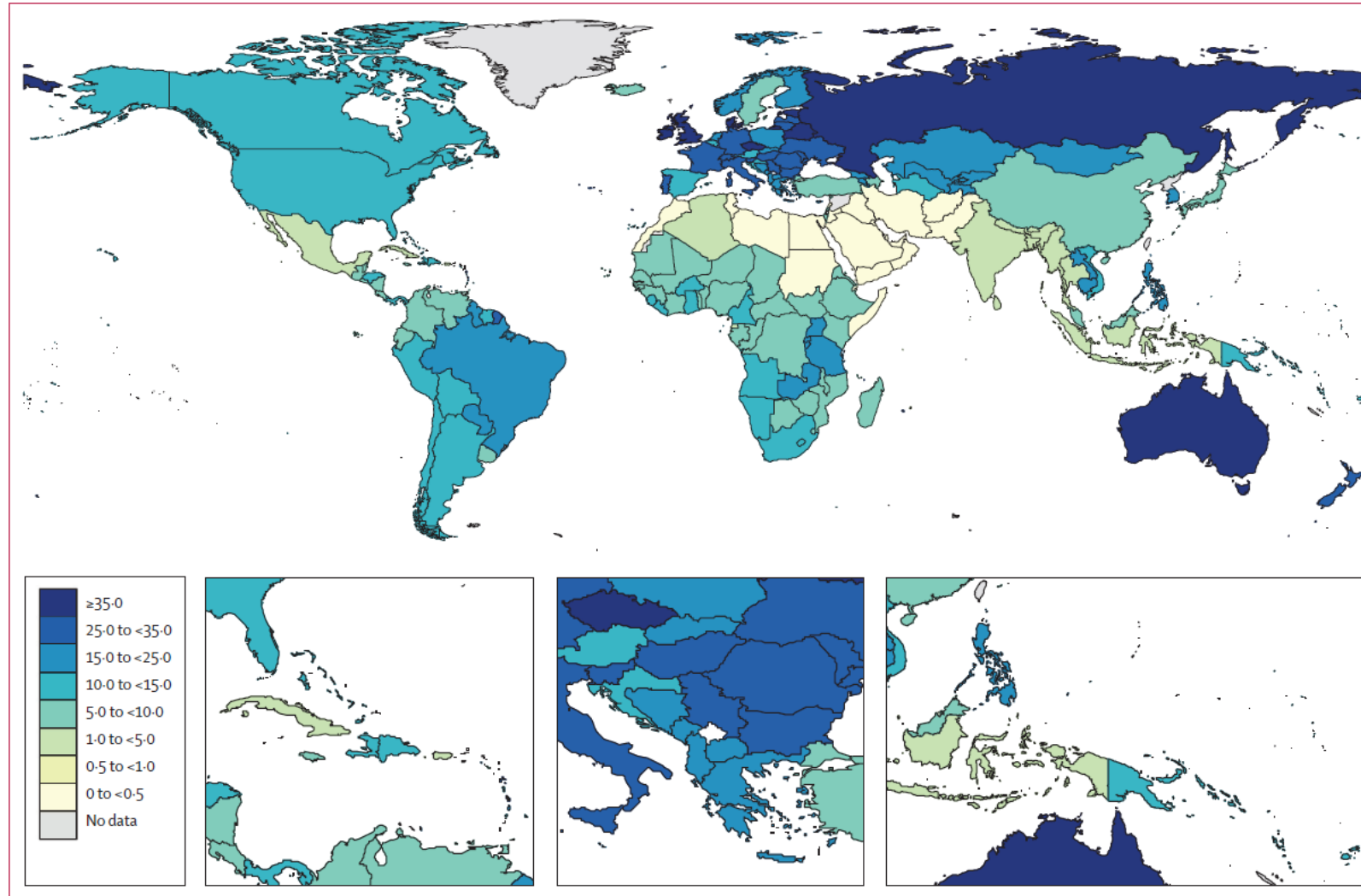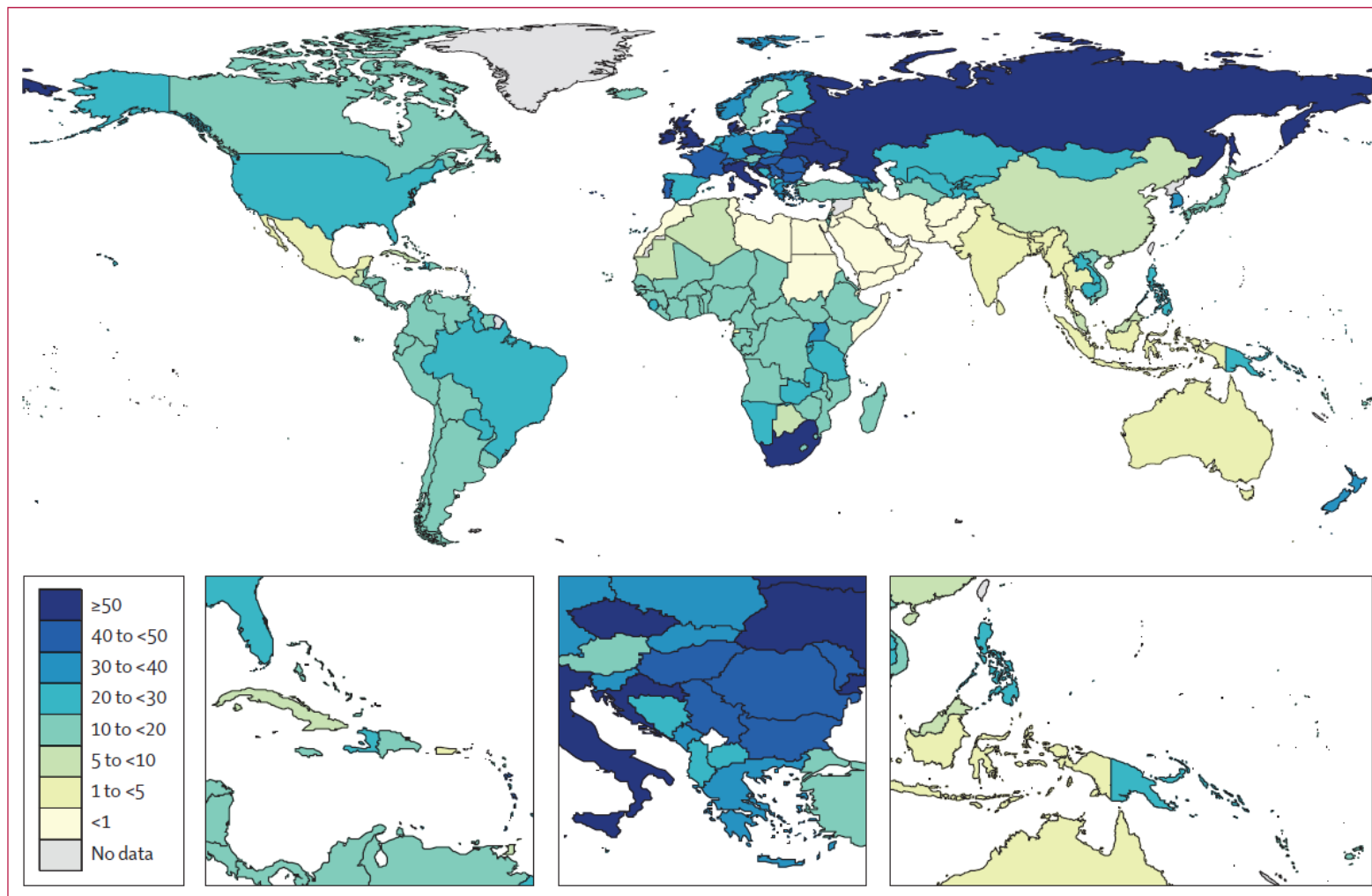
Fetal Alcohol Syndrome (FAS)

Specific pattern of minor facial anomalies

Pre- and/or postnatal growth deficiency: height or weight <10%

Evidence of central nervous system dysfunction: structural brain abnormalities or head circumference <10% or recurrent non-febrile seizures

Neurobehavioral Impairment: Neurocognitive or Neurobehavioral impairment or Developmental Delay (for children <3)

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Global prevalence (per 10 000 people) of FAS among the general population

Source: Popova et al, 2017

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Global prevalence of alcohol use (any amount) during pregnancy and fetal alcohol syndrome (FAS) in the general population in 2012, by WHO region

	Alcohol use during pregnancy (%)	FAS (per 10 000)
AFR	10·0% (8·5–11·8)	14·8 (8·9–21·5)
AMR	11·2% (9·4–12·6)	16·6 (11·0–24·0)
EMR	0·2% (0·1–0·9)	0·2 (0·2–0·9)
EUR	25·2% (21·6–29·6)	37·4 (24·7–54·2)
SEAR	1·8% (0·9–5·1)	2·7 (1·3–8·1)
WPR	8·6% (4·5–11·6)	12·7 (7·7–19·4)
Worldwide	9·8% (8·9–11·1)	14·6 (9·4–23·3)

Data are prevalence estimates (95% CI). AFR=African region. AMR=Region of the Americas. EMR=Eastern-Mediterranean region. EUR=European region. FAS=Fetal alcohol syndrome. SEAR=South-East Asia region. WPR=Western Pacific region.

highest estimated prevalence of alcohol use during pregnancy were:
Russia 36.5%,
UK 41.3%,
Denmark 45.8%,
Belarus 46.6%,
Ireland 60.4%,

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Fetal Alcohol Spectrum Disorders

Fetal alcohol syndrome (most severe)

Partial FAS (some defects)

Alcohol-related neurodevelopmental disorder (no facial dysmorphology)

Alcohol-related birth defects

In the normal range, but never reach their potential (largest number of cases)

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Secondary disabilities

- **Individuals with FASD suffer from many physical, cognitive, emotional, and social problems, which affect daily functioning and result in adverse life outcomes.**
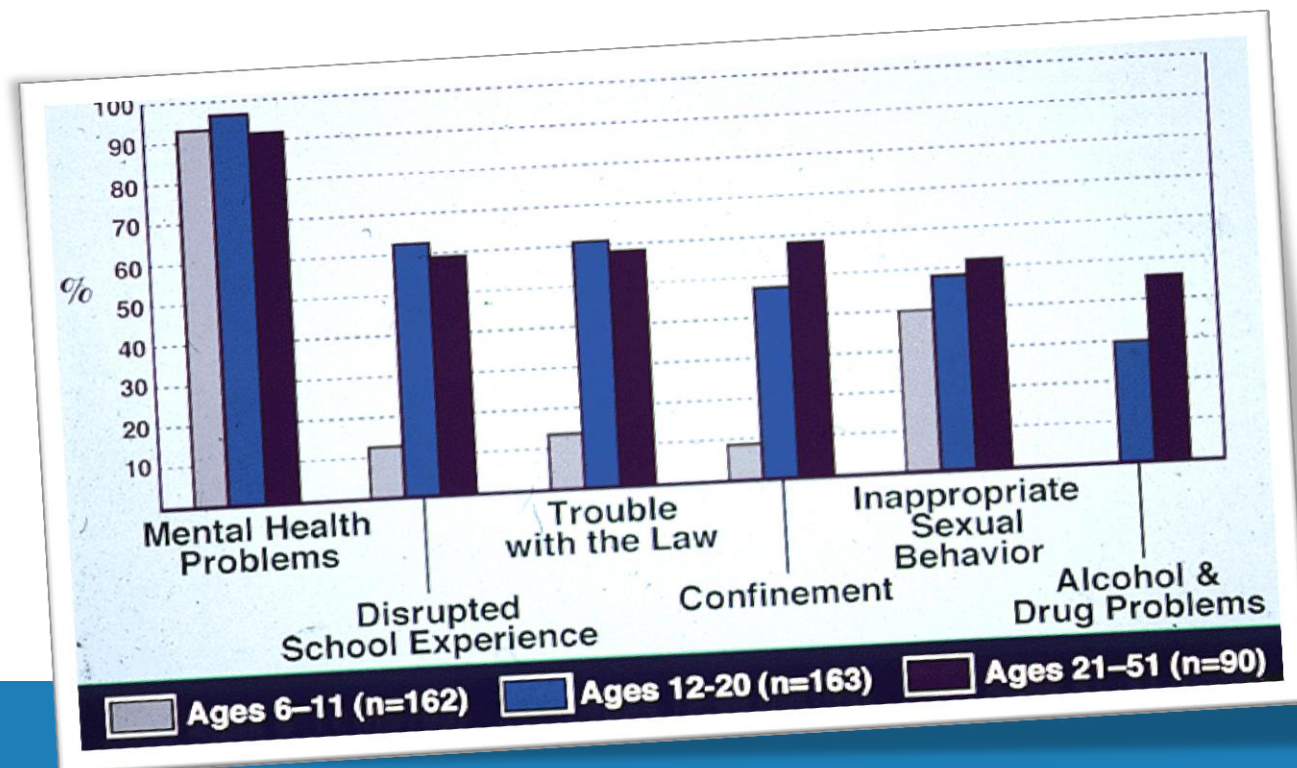
- **Protective factors:**
  - **Diagnosis before age 6**
  - **Stable and nurturing home environment**
  - **No physical/sexual abuse**
  - **Access to Developmental Disabilities services**

(Streissguth, et al., 1996, 2004)

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FAS and FASD remain under-diagnosed

- Facial features are subtle, particularly in newborns

- The neurobehavioral deficits necessary for diagnosis may not be obvious <age 3 years

- In epidemiology, one approach that has been used to obtain more accurate prevalence is Active Case Ascertainment

- It involves assessment among an entire, or representative sample population such as all 1st grade school entry students

- It is the most expensive in money and time – but it affords the most reliable prevalence rates

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WHO International Collaborative Research Project on Child Development and Prenatal Risk Factors with a Focus on Fetal Alcohol Spectrum Disorders: Goals

- Generate new knowledge on prevalence of FASD among children of 7-9 years old and prevalence of prenatal risk factor exposure (focus on alcohol)
  - Data collection in Canada, Namibia, Poland (modified protocol), Ukraine, Republic of Belarus, Republic of Moldova and Seychelles.

- Raise awareness of FASD and strengthen capacity for prevention and identification of FASD and promote treatment and support of affected individuals and families

- Support international collaboration, networking and partnerships for advancing FASD-related research globally.

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Study design and primary study objectives

- Design: observational cross-sectional study with the following primary objectives:

1. Estimate the prevalence of neurodevelopmental conditions known as Fetal Alcohol Syndrome (FAS) and Fetal Alcohol Spectrum Disorders (FASD) by determining the prevalence of FAS/FASD among children (7-9 years of age) using an active case ascertainment approach

2. Determine the prevalence of prenatal risk factor exposure with a focus on alcohol consumption using maternal data and/or biomarkers of prenatal alcohol exposure (optional).

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Secondary study objectives

- Assess in the study sites the practicality, reliability, and cost-effectiveness of the proposed approaches for estimating the prevalence of FASD.

- Identify the most suitable and cost-effective procedures for estimating and monitoring the incidence and prevalence of FASD.

➢ The point prevalence of children with FASD may be higher before the age of seven, due to the higher mortality rate observed among FASD-affected individuals compared to children without FASD. This limitation should be acknowledged.

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Sample size

~2,500 children at each site (assuming an FASD prevalence of 6 per 1,000)

The total population living in the sampling area should be at least 75 K-100 K people, in order to allow for a sufficient number of 7-9 year-old children in the respective sampling area (based on the WHO world standard population).

The age range of 7-9 can be expanded to 7-12 year-old children if there are not likely to be enough 7-9 year-old children in the sampling area to meet the sample size requirements.

Sampling frames in the study

- **Regular schools, orphanages and health care settings (regular health checkups):** Children of 7-9 years attending: a) Regular schools or schools in orphanages; and/or b) Regular health checkups in local health care settings

- **Mental health institutions:** Children of 7-9 years with mental retardation and other clinically significant mental and behavioural disorders in contact with mental health and social services: a) Disabled children in residential treatment and care; b) Disabled non-institutionalized children; and/or c) Non-disabled children in contact with mental health and social services.

- **Special educational institutions:** Children of 7-9 years with other disabling conditions and special needs, including children from special schools and special educational programs.

➢ There might be some overlapping between the samples

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What we expect using three sampling frames

- Different FASD prevalence in each of them

- FASD prevalence estimates will be reported separately for each sampling frame

- The estimates produced from the three sampling frames will be combined in order to arrive at an overall FASD prevalence estimate of the target sampling area

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Assessment instruments and procedures

Phase I: Pre-screening

      a) growth deficit and

      b) behavioural and/or learning difficulties

Phase II: Active case ascertainment

    a) Dysmorphological assessment

    b) Neuropsychological and behavioural assessment

- *The Wechsler Abbreviated Scales of Intelligence (WASI-II);*

- *The Wechsler Intelligence Scale for Children IV (WISC-IV)*

- *Developmental NEuroPSYchological Assessment (NEPSY-II)*

- *Child Behaviour Checklist (CBCL) and The Vineland Adaptive Behaviour Scales II*

    c) Collection of data on maternal alcohol drinking history

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Communication of results

➢ Results of the FASD screening as well as health and social care recommendations of children diagnosed with FASD will be provided to the parents/guardians as part of the general health checkup (for children in sampling frame 1) or additional clinical and neuropsychological examinations (for children in sampling frames 2 and 3)

➢ This communication to parents/guardians will include recommendations on referrals to local health services, social services and educational programs for further diagnostic evaluation and, if necessary, for special treatment and social support.

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Timeline

	1st year				2nd year				3rd year			
	1 to 3	4 to 6	7 to 9	10 to 12	13 to 15	16 to 18	19 to 21	22 to 24	25 to 27	28 to 30	31 to 33	34 to 36
Method 1: ACA*												
Ethics approval												
Hiring and training of RAs* and HPs*												
Quality monitoring and data collection												
Data entry												
Data analysis												
Report												
Publications, conferences												
Method 2: Prenatal alcohol exposure												
Ethics approval												
Hiring and training of nurses												
Quality monitoring and data collection												
Laboratory testing												
Data entry												
Data analysis												
Report												
Publications, conferences												

*ACA – active case ascertainment; HP – health professional; RA - research assistant

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WHO Guidelines for the identification and management of substance use in pregnancy

- Released in March 2014.

- Covers alcohol and drugs.

- Contains principles and recommendations on screening, brief interventions, pharmacological and psychosocial treatment, breastfeeding.

Guidelines for the identification and management of substance use and substance use disorders in pregnancy

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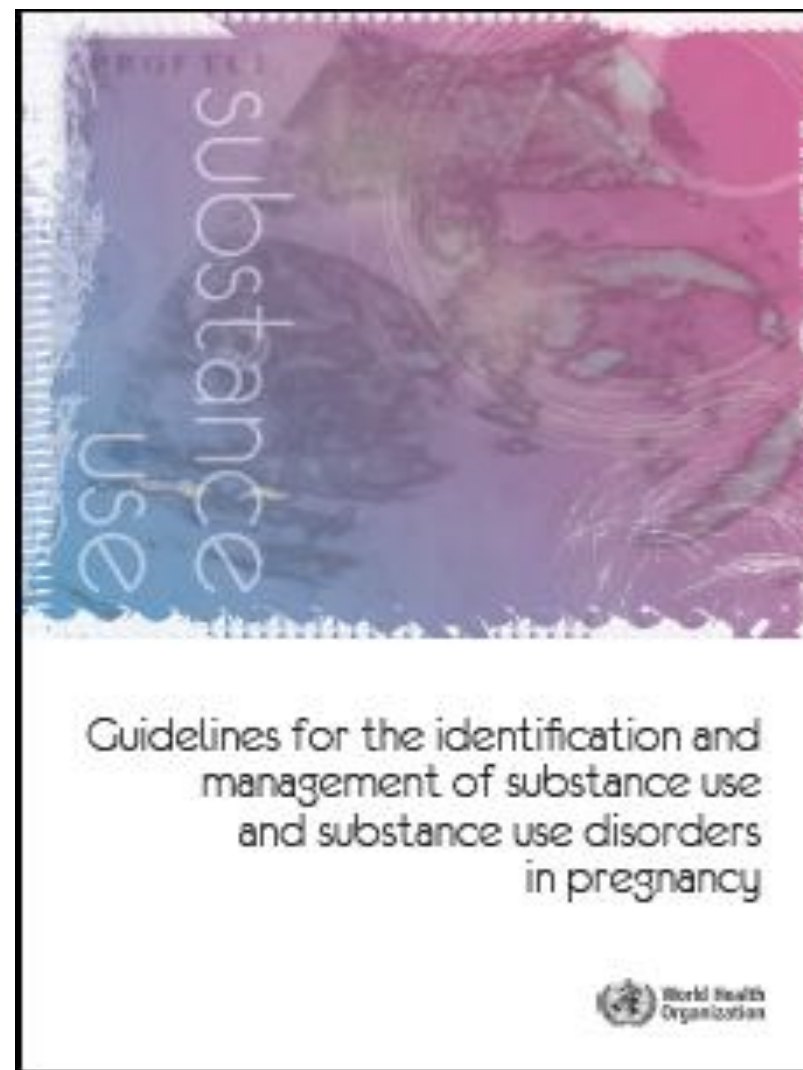
WHO Guidelines for the identification and management of substance use in pregnancy: Overview

- Impact of substance use in pregnancy

- Epidemiology of substance use in pregnancy

- Guidelines development process

- General principles of care

- Recommendations
  - Use and Harmful Use
  - Dependence
  - Neonatal withdrawal syndrome
 - Breastfeeding

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Project on dissemination of "pregnancy" guidelines

- ● **Implemented in collaboration with UNODC**

- ● **Supported by the US State Department**

- ● **Main deliverables:**
  - – Clinical tool based on the recommendations contained in the WHO Guidelines covering alcohol, drugs and tobacco
  - – Training package for effective dissemination and implementation of the WHO Guidelines
    - • First testing in Brazil, December 2016
  - – Support development of treatment programs for drug dependent pregnant women based on the WHO guidelines.

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The most recent WHO guidance on antenatal care (November 2016)

- **Addresses broad range of issues:**

  A. Nutritional interventions

  B. Maternal and fetal assessment

  C. Preventive measures

  D. Interventions for common physiological symptoms

  E. Health systems interventions to improve the utilization and quality of ANC

- **Incorporates recommendations for substance use from WHO guidelines on identification and management of substance use and substance use disorders.**

WHO recommendations on antenatal care for a positive pregnancy experience

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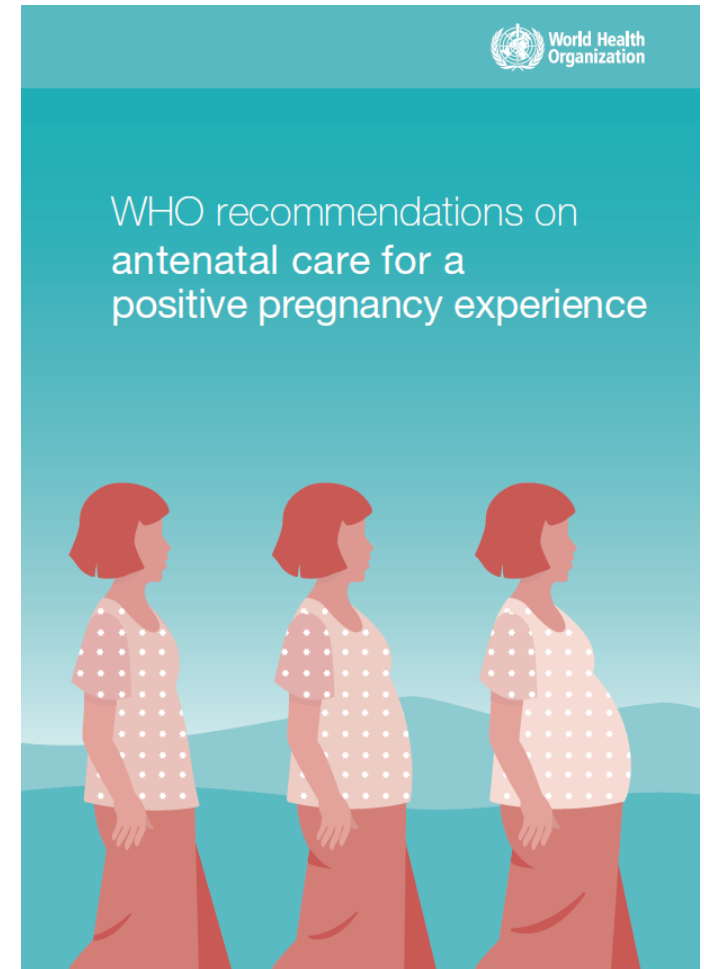
The Key Challenges

- Recognizing that 50% of pregnancies are unplanned so that substantial prenatal alcohol exposure may have occurred before pregnancy recognition

- Determining the most effective approaches to incorporate interventions for at-risk drinking into pre-pregnancy and prenatal care

- Mounting health education efforts in the medical community, among public health officials, legislators and the public to inform them of the risks that that alcohol may cause to the embryo and fetus.

- Working to change the social norms surrounding drinking behavior whenever there is a risk of a pregnancy

- Stigma

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- PARPA, Poland, for hosting the meeting of PIs

- PIs in countries (Belarus, Canada, Moldova, Namibia, Poland, Seychelles, Ukraine.

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Further information at:

http://www.who.int/substance_abuse/

http://www.who.int/mental_health/en/