Распространенность Фетального Алкогольного Спектра Нарушений (ФАСН) в Мире ВОЗ Международный Совместный Исследовательский проект по проблеме ФАСН

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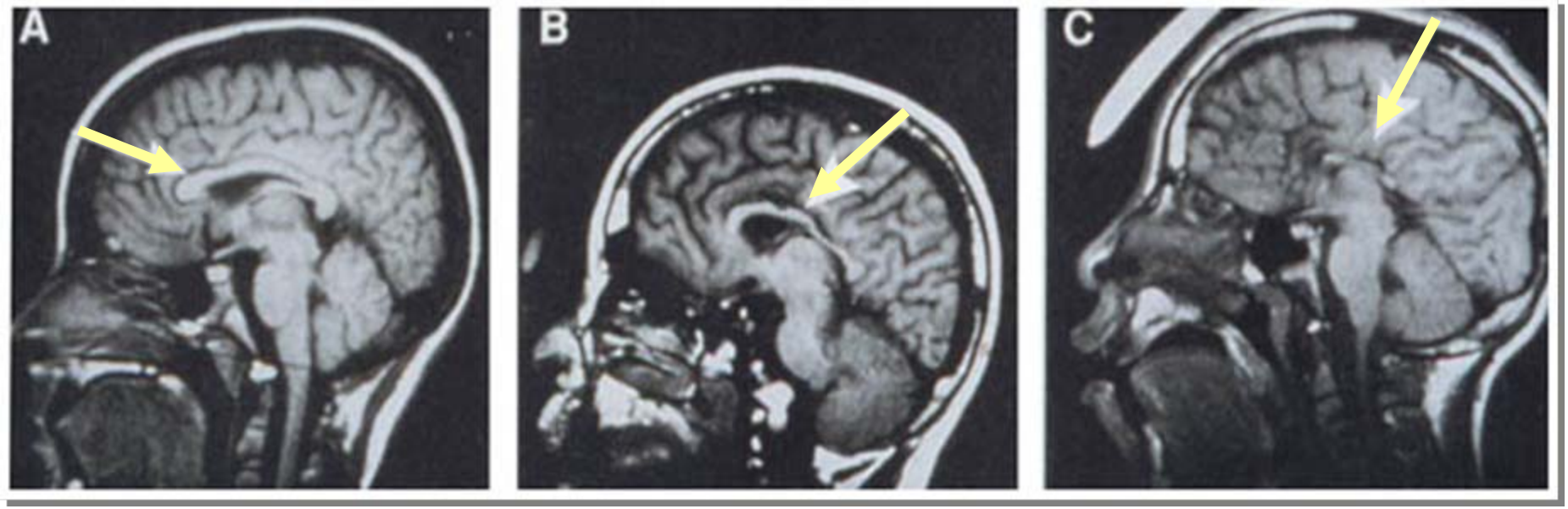
Школа профилактики ФАСН

Организаторы: ФГБУ ЦНИИОИЗ Минздравсоцразвития России и Ассоциация «Врачи мира» Франция при поддержке Посольства Франции в России

Посольство Франции в России, 23-24 января 2012 г.

Большая Якиманка, 45, зал *Salon d'honneur*

Prenatal alcohol exposure can permanently damage the brain affecting important structures such as the cerebellum and corpus callosum



Normal **FAS** **FAS**

Permanent loss of the tissue indicated by the arrows (portions of the corpus callosum)

Images courtesy of Dr. S. Mattson
NIAAA

ФАСН является главной причиной нарушений умственного развития

Первичные проблемы

- **трудности в обучении – плохая память, проблемы с пониманием смысла слов, счета и числовых обозначений**
- **проблемы со зрением, ушные инфекции, роблемы с зубами и прикусом**
- **проблемы с поведением – колебания настроения, импульсивность, сниженное внимание, отсутствие самодисциплины, ответственности, а также трудность в принятии социальных норм и установлении межличностных отношений**
- **снижение интеллекта - коэффициента интеллекта (IQ) - 60 ед.**

Вторичные проблемы

- **По мере взросления - психические заболевания, наркозависимость, неприятности с законом и неспособность к самостоятельной жизни**

FASD is one of the leading causes of mental deficiency and birth defects in Canadian children (PHAC, 2005)

- **Primary disabilities:**
  permanent brain injury, learning disorders, developmental disabilities, maladaptive behaviours, physical malformations, and growth restriction

- **Secondary disabilities:**
  early school dropout, addiction problems, poorly recognized mental health conditions, promiscuous sexual behaviour, and trouble with the law

FASD is associated with more than 200 diseases coded in the International Classification of Diseases (Popova et al., in preparation)

High susceptibility to delinquency, drug abuse, criminal behavior and victimization

60% of adults with FASD met criteria for current or past alcohol or drug dependence (Famy et al., 1998)

10-17% offenders in Canada have FASD (MacPherson and Chudley, 2007)

Youths with FASD are *ninteen times* more likely to be incarcerated than youths without FASD in any given year (Popova et al., 2011, *Canadian Journal of Public Health*)

At the chronological age of 18 the cognitive and adaptive skills of those with FASD may be at age 10 or younger

Women with FASD are likely to give birth to a child with FASD

- **Women with FASD are likely to drink while pregnant, give birth to a child with FASD, and do not maintain custody of their children.**

- **In a sample of 415 patients with FASD, 30 females gave birth to a child. Of these, 40% were drinking during pregnancy, 17% had children diagnosed with FASD, an additional 13% had children who were suspected of having FASD, and 57% no longer had the child in their care (Streissguth et al., 1996).**

Significant proportion of pregnancies in Canada are alcohol-exposed

-14% in the general population of Canada (PHAC, 2005)
-49% in Alberta, isolated Northern community (Dow-Clarke et al., 1994)

Binge drinking is more common among Aboriginal women (10.2% reported weekly heavy drinking; The Ontario First Nations Regional Population Health Survey, 2007)

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Prevalence of FASD
Objectives of the Study

-To conduct a systematic search of the world literature on all existing studies reporting the prevalence and/or incidence of FAS and FASD

-To update the overall estimates of the prevalence rates of FASD based on existing studies and to compare these rates between different countries

Previous Pooled Studies

A few studies exist:

Western society:

Abel & Sokol (1987): FAS incidence of 1.9 per 1,000 live births

Abel & Sokol (1991): FAS incidence of 0.33 per 1,000 live births

Worldwide:

Abel (1995): FAS incidence rate of 0.97 cases per 1,000 live births

US:

May et al. (2009): FAS prevalence in typical, mixed-racial, and mixed-socioeconomic populations of the US is 2 to 7 per 1,000

Canada:

Roberts and Nanson (2000): Crude prevalence of FAS is 1-2 per 1,000 live births

Public Health Agency of Canada (2003): Crude prevalence of FASD is 9 per 1,000 live births

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Method

Systematic literature review

- **Studies with estimations of the rates of FAS/FASD**
- **Searched multiple electronic bibliographic databases:**

  Ovid MEDLINE, PubMed, EMBASE, Web of Science (including Science Citation Index, Social Sciences Citation Index, Arts and Humanities Citation Index), PsycINFO, ERIC, CINAHL, OVID (combines several databases), the Cochrane Database of Systematic Reviews, Canadian Centre on Substance Abuse Library Collection Database, Centre for Addiction and Mental Health Library Database, and Google Scholar http://scholar.google.com)

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Results

The data on rates of FAS were available from only 22 countries (78 studies)

Countries:

Australia, Brazil, Canada, Chile, Croatia, Denmark, Ireland, Finland, France, Germany, Hungary, Italy, New Zealand, Portugal, Russia, South Africa, Spain, Sweden, Switzerland, UK, Uruguay, and USA

0 per 1,000 in the general population of Australia (Harris & Bucens, 2003) to 68.0-89.2 per 1,000 among 1st grade students in South Africa, Western Cape (May et al., 2007)

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Results (cont')

- **The pooled overall FAS birth prevalence:**

  0.5 per 1,000 live births

- **The pooled prevalence of FAS for all age groups:**

  0.3 per 1,000 live births

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Results (cont')

Prevalence varies widely depending on the STUDIED POPULATION

Heavy drinking women

The birth prevalence and prevalence for all age groups of FAS among heavy drinking women in all countries included in this analysis were much higher as compared to the general population

- Overall birth prevalence: 71.3 per 1,000 live births
- Prevalence of FAS for all age groups: 97.0 per 1,000

  (143 to 323 times higher as compared to the general population)

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Results (cont')

Aboriginal populations

Reported rates of FAS were consistently higher in aboriginal than non-aboriginal populations

Pooled prevalence of FAS for all age groups in aboriginal populations was 13 times higher than in non-aboriginal populations of Australia, Canada, & USA combined

Example for Canada:

Crude prevalence of FAS is 1-2 per 1,000 live births in general population (Roberts and Nanson 2000)

Prevalence of FAS is 190 per 1,000 live births in Aboriginal population of BC (Robinson et al., 1987)

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Results (cont')

SELECTED COUNTRIES

The prevalence of FAS for all age groups in Europe among the general population was:

- **12 times higher than in Australia and New Zealand; &**
- **10 times higher than in the USA**

Estimation of prevalence of FAS in the Global Burden of Disease regions (GBD Group)

- Data on the prevalence of FAS for 2005 for 16 European countries were extracted from EUROCAT European network of population-based registries for the epidemiologic surveillance of congenital anomalies. (http://www.eurocat-network.eu/)
- The countries were: Austria, Belgium, Czech Republic, Denmark, Finland, France, Great Britain, Hungary, Ireland, Italy, Malta, Netherlands, Norway, Poland, Portugal, and Ukraine
- The data were analyzed using a Generic Disease Modeling System (DisMod III; Disease Modeling)

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Method

What is DisMod?

- Disease Modeling
- The Institute of Health Metrics and Evaluation's (Independent Research Center at the University of Washington)
- Produces consistent estimates for epidemiological parameters of a disease with accurate uncertainty intervals
- Based on a simple four-compartment model of how a disease moves through a population.
- Enables to combine data from multiple sources to reduce errors in the data that are available, reconcile the data that are inconsistent, and impute or forecast the data that are absent altogether

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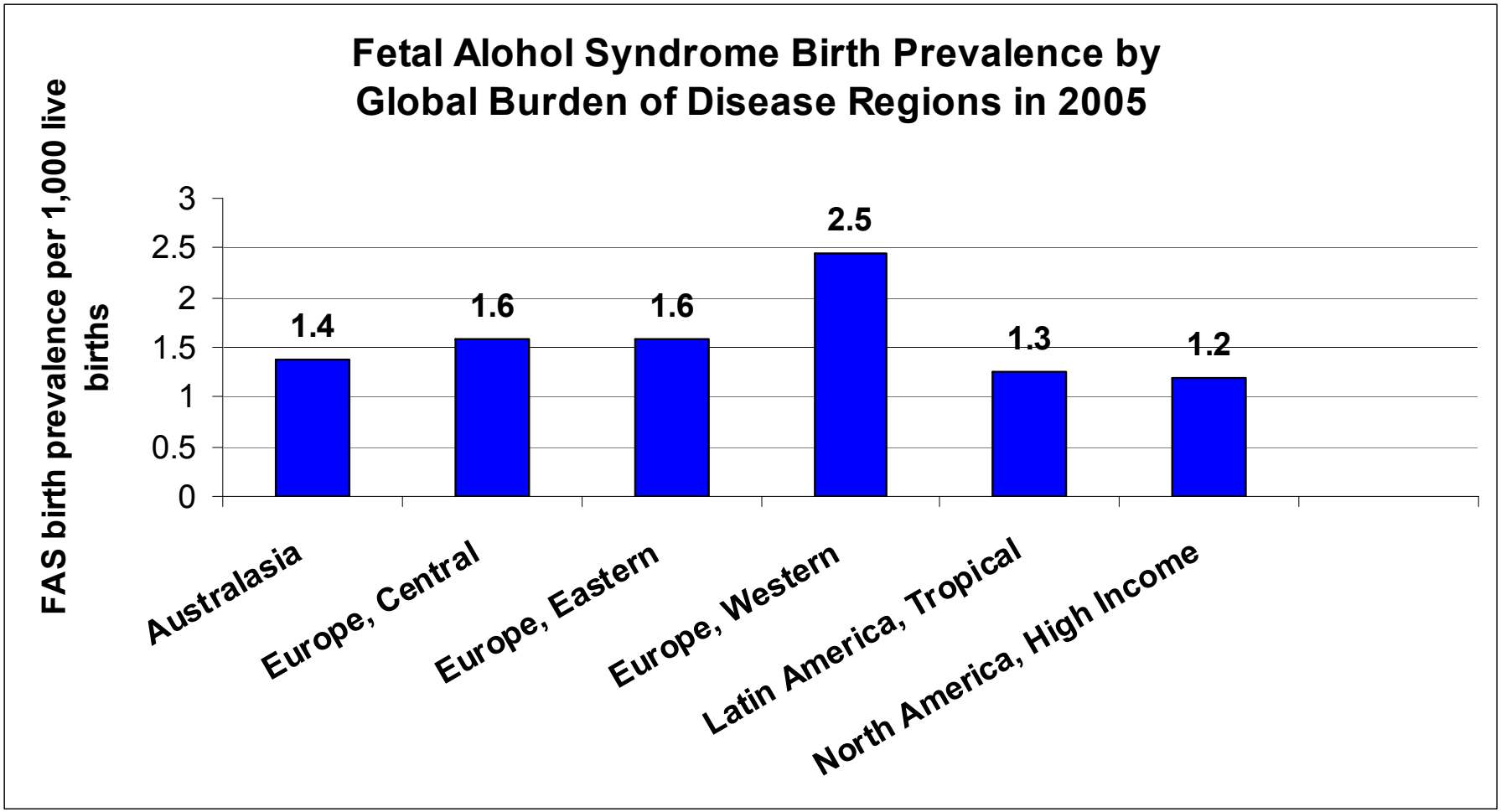
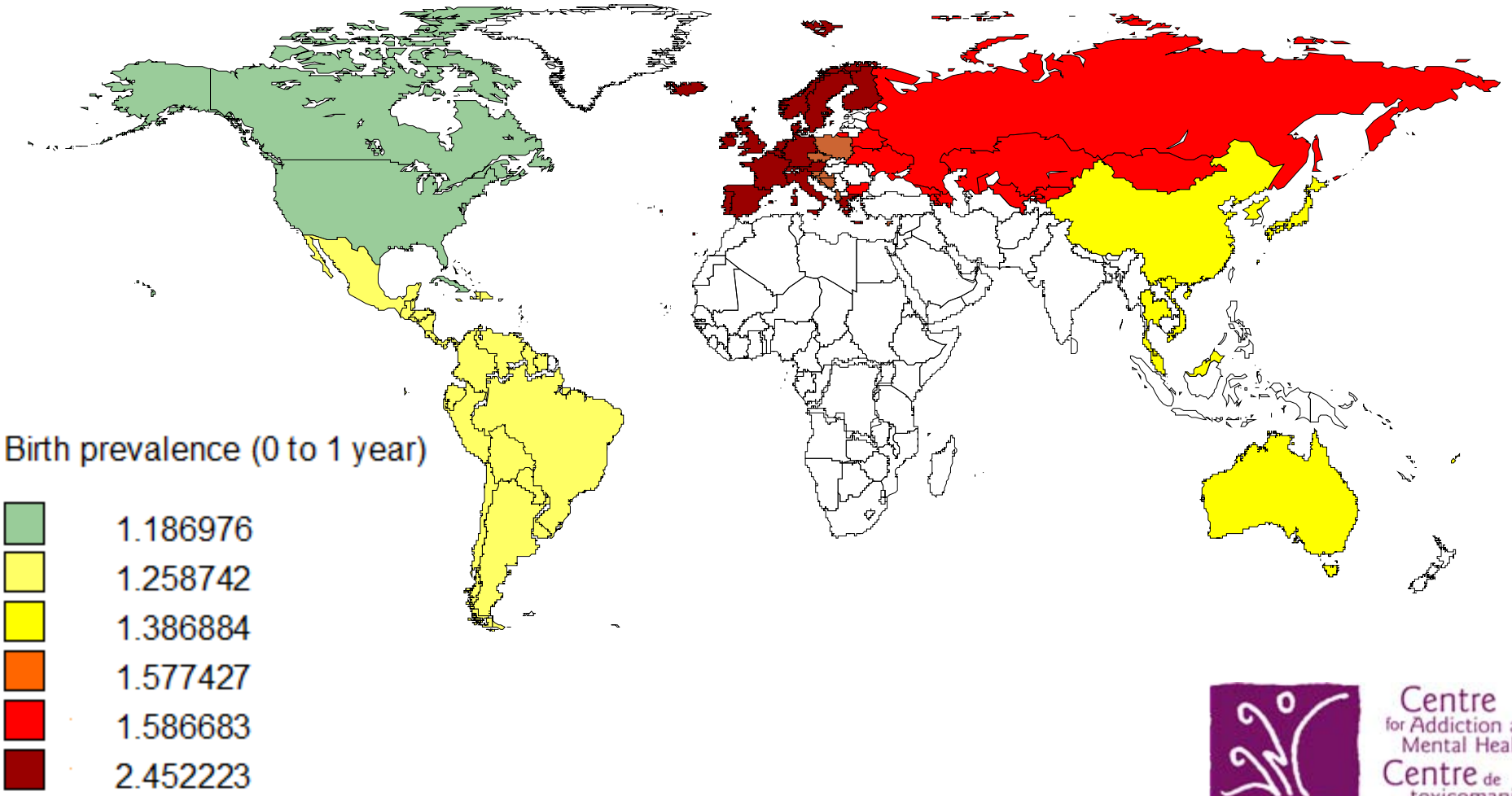
Preliminary Results



Preliminary Results (cont')

FAS birth prevalence per 1,000 live births by GBD regions



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Conclusion

Our preliminary pooled estimates for FAS based on the published studies are close to the previous overall FAS incidence rate (0.33/1,000) as estimated by Abel and Sokol (1991)

GOOD or BAD?

A large proportion of pregnant women in many countries STILL consume alcohol

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Conclusion (cont')

- Urgent need to monitor and effectively lower the rate of these conditions in the world
- Data on incidence/prevalence of FAS/FASD are completely absent for the majority of countries
- Existing data from only 22 countries are often imprecise and confusing
- Need for valid and reliable epidemiological studies in order to estimate the global prevalence of FASD

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Why is it important to detect children/adults with FAS/FASD?

Annual and lifetime cost per individual associated with FASD in Canadian studies (CND; Adjusted for inflation January 2009)

Reference	Year of study	Prevalence	Age	Annual cost (95% CI)	Annual cost per individual (95% CI)
Stade et al 2006	2003	3	1-21	$386.6M	$16,105 ($14,582-$17,627)
Stade et al 2009	2007	3	0-53	$5.5B ($4.2B-$6.6B)	$22,260 ($20,409-$24,728)
Than & Jonsson 2009 (based on Stade et al 2006)	Various years, Alberta	3-9 incidence	0-72	$148.4M-$428.4	$1.23M (lifetime cost per individual)

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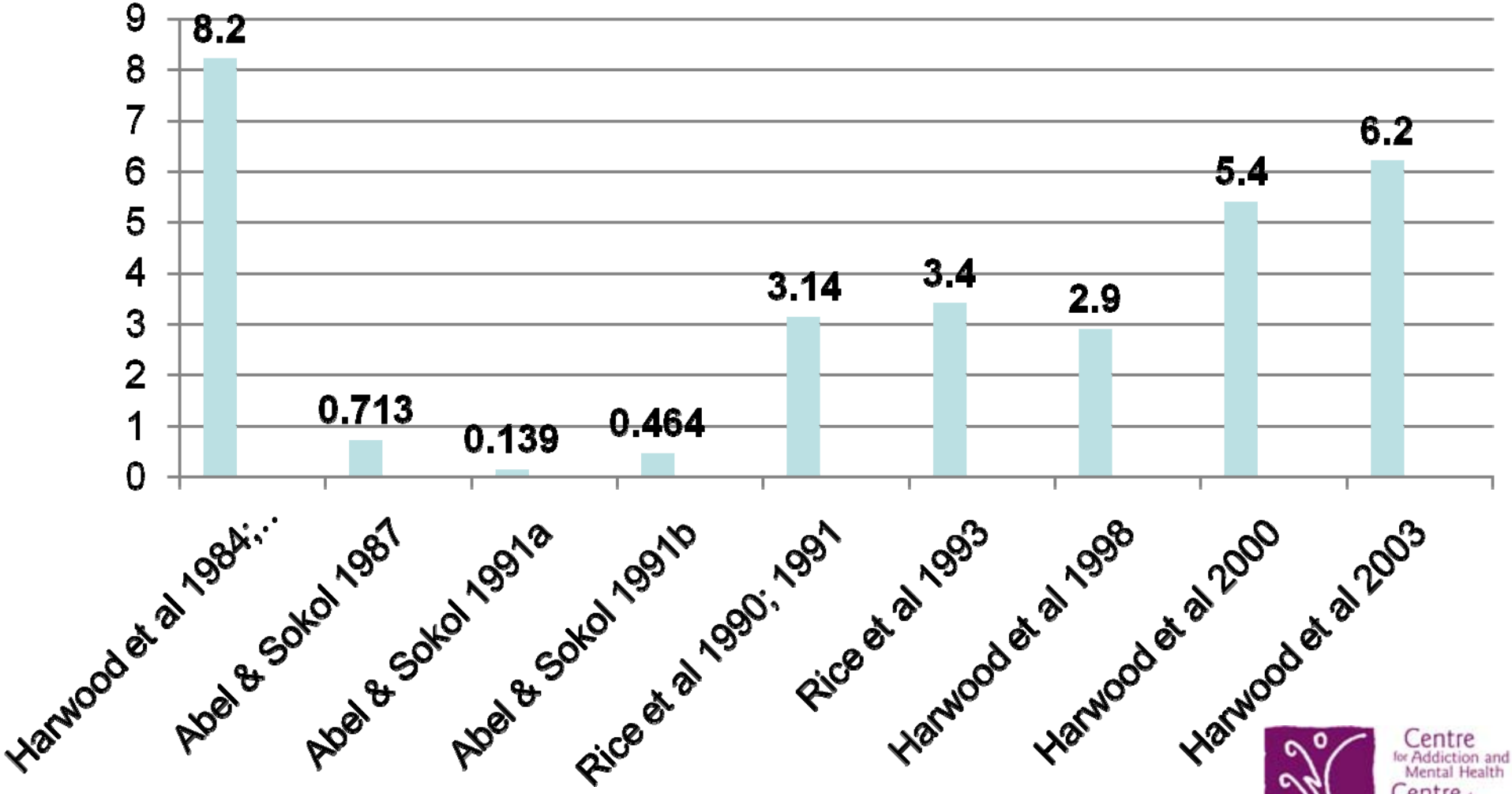
Results from the USA studies

Annual Cost associated with FAS in the USA studies (USD; Adjusted for inflation Jan 2009)



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Results from the USA studies (cont')

Lifetime cost per individual associated with FAS (USD; Adjusted for inflation Jan 2009)

Harwood & Napolitano (1985)

$1.5 M

Weeks (1989) for Alaska

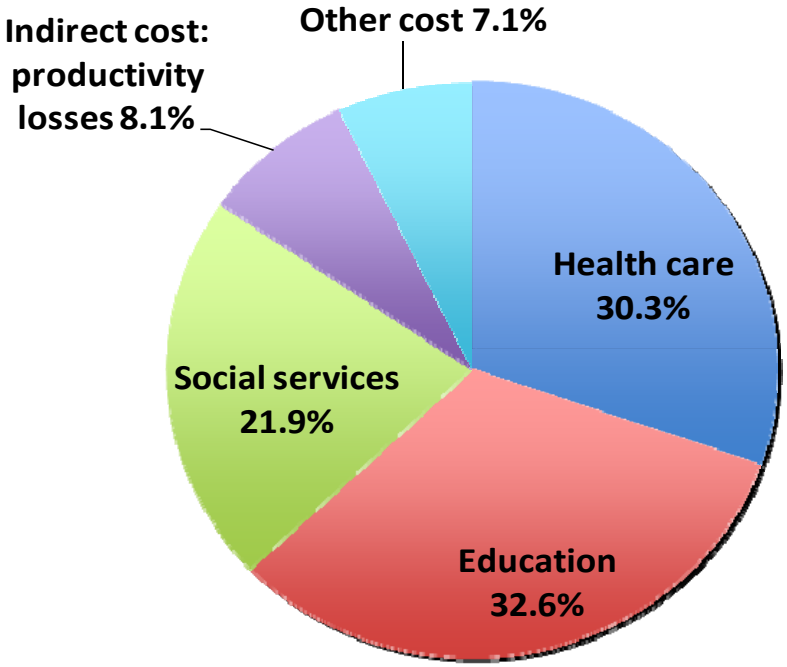
$2.5M

Economic Cost of FASD

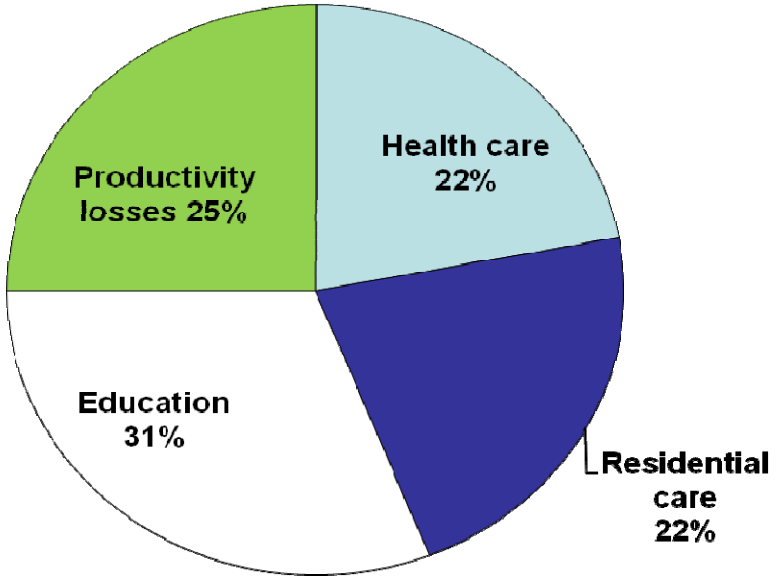
Annual costs associated with FASD exceed $5.3 billion (Stade et al. 2009) Underestimated!

Lifetime cost per individual $1.23M (Than & Jonsson 2009) Underestimated!

Canadian studies



USA studies



Why is it important to detect children/adults with FAS/FASD?

The cost of inaction is high

Identification and diagnosis pave the way for interventions and supports, which may help prevent secondary disabilities. These include mental health problems, disruptive school experiences, trouble with the law, dependent living and inappropriate sexual behaviour

The earlier the child is identified and diagnosed, the better

Having a diagnosis of FAS is a protective factor

Early diagnosis and providing an appropriate environment decreases these risks up to four fold

(e.g., Burd et al., 2003)

Determining the prevalence and incidence of FAS and FASD in the selected countries

(World Health Organization)

PI: Vladimir Poznyak (WHO); Co-PIs: Svetlana Popova; Jürgen Rehm

WHO meetings for the project "Alcohol, Health and Development: Agenda for International Research"

1) Proposal presented: September 2009 Stockholm, Sweden

2) Proposal finalized: November 2-3, 2010, Kerkrade, The Netherlands, November 2-3, 2010

Leading world researchers of FASD field and representatives of the largest 18 countries of the world

Tentative participants: African countries (TBD), Belarus, Brazil, Canada, Chile, Kenya, Moldova, Poland, Russia, Spain, and Ukraine

Основные цели

Цель 1:

- Оценить распространенность фетального алкогольного синдрома (ФАС) и фетального алкогольного спектра нарушений (ФАСН) путем оценки распространенности ФАС/ФАСН среди детей (7-9 лет) с помощью метода активного выявления случаев.

Цель 2 (по выбору):

- Определить распространенность пренатального воздействия алкоголя на плод с помощью данных об употреблении матерью алкоголя во время беременности и/или с помощью биомаркеров воздействия алкоголя на плод во внутриутробном периоде.

Основной Диагностический Метод

Анализе выборки детей 7-9 лет, проживающих в определенном районе

Активное Выявление Случаев является основным диагностическим методом проекта

Выборка

Дети 7-9 лет, посещающие:

I а) Общеобразовательные школы и школы, при детских домах

б) Регулярные медицинские осмотры в местных лечебных учреждениях (например, поликлиниках)

II Дети 7-9 лет с отставанием психического развития и другими выраженными психическими или поведенческими нарушениями, получающие помощь в медицинских учреждениях психиатрического профиля и службах социального обеспечения

III Дети 7-9 лет с другими инвалидизирующими расстройствами и нуждающиеся в специальном обеспечении, включая детей из специальных школ и специальных образовательных программ

Method: ACA

Data collection

Phase I pre-screening

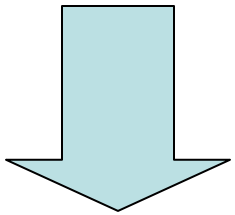
(to determine the eligibility for dysmorphology assessment)

- Height, weight, and head circumference [occipitofrontal circumference (OFC)]

- Referrals from teachers/caregivers based on learning or behavioural problems (the Neurobehavioural Screening Tool; Canadian Association of Pediatric Health Centres, 2010).

Method: ACA
Data collection

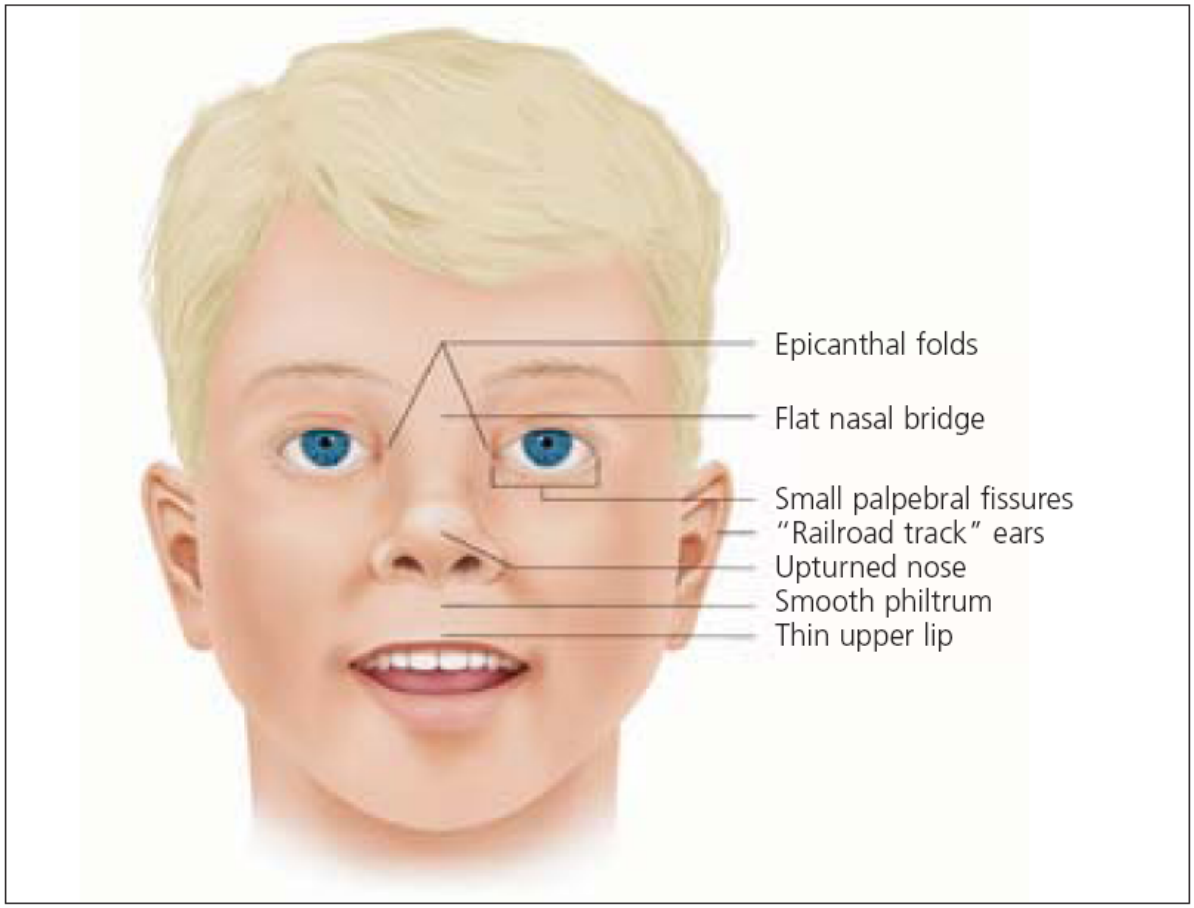
- height or weight or OFC at or below the 10th percentile or
- other suspected neurodevelopmental abnormalities and/or
- positive on the Neurobehavioural Screening Tool



Phase II:

1) dysmorphology assessment
2) psychological and behavioural testing

Dysmorphology assessment
Specific Facial Phenotypic Features



Presence of 1 of the 3 specific facial phenotypic features:

1) **short eye openings (palpebral fissures),**
2) **smooth or flattened philtrum,**
3) **thin upper lip**

Method: ACA
Dysmorphology Assessment (con't)

- Digital facial photographs for all screened children will be taken
- Informed consent from parents or caregivers
- FAS Facial Photographic Analysis Software (version 1.0) (FAS Diagnostic and Prevention Network, FAS, NDP, University of Washington, Seattle, Washington, 2003) http://depts.washington.edu/fasdpn/htmls/face-software.htm
- cost-effective
- allows for a distant diagnosis
- can be e-mailed to one particular centre in one country where the images can be centrally analyzed

Method: ACA

FAS Facial Photographic Analysis Software (www.fasdpn.org)

How to Take the Three Photographs
(Front View) (Angle View) (Side View)

frontal 3/4 view lateral

Standardized Photo Set

Method: ACA

Maternal alcohol history in pregnancy

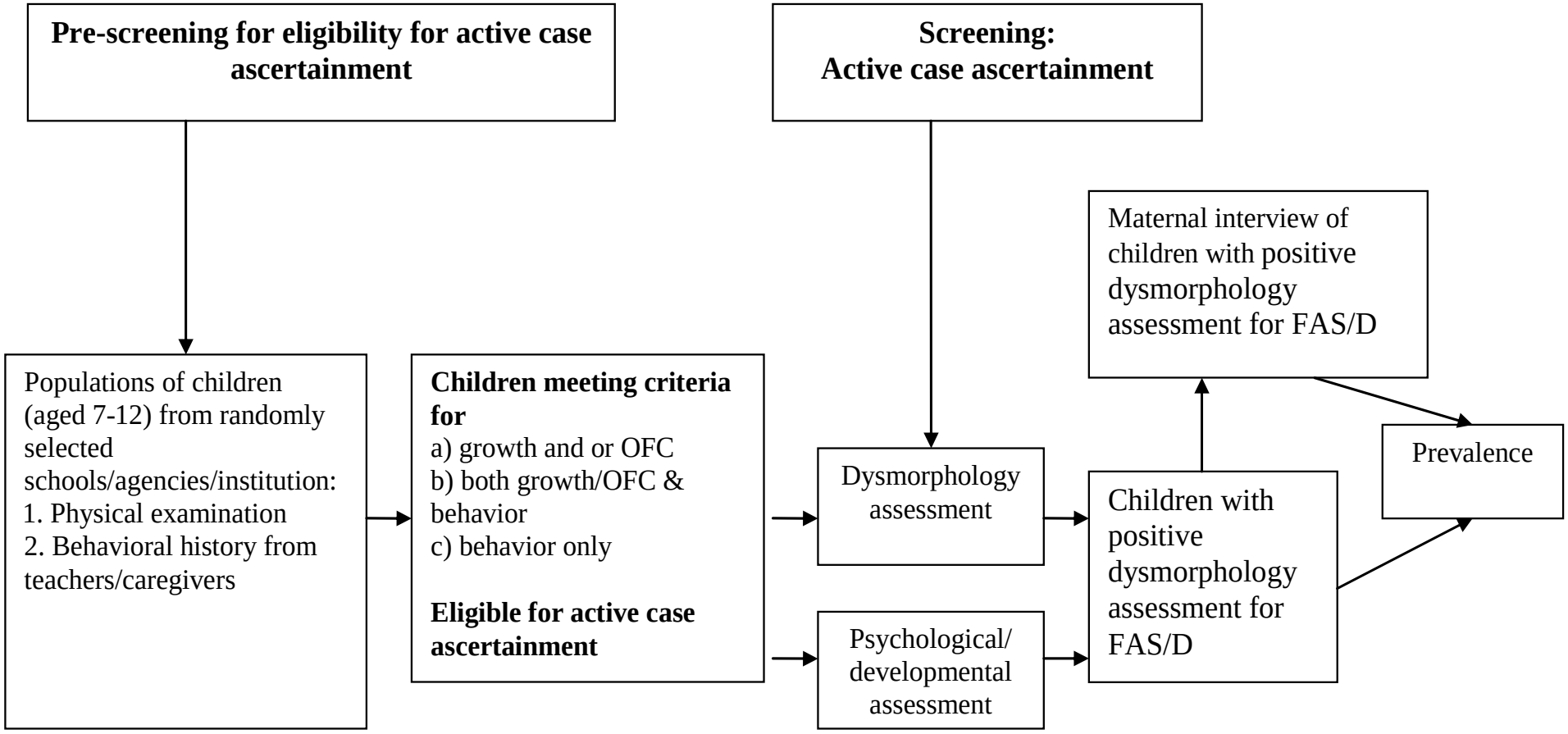
- FAS – confirmation is not required
- Partial FAS - confirmation is required
- ARND - confirmation is required

- The information on maternal alcohol use history in pregnancy may also be obtained from health care providers, medical documentation or other appropriate sources of information

Method: ACA
Diagnostic criteria

- The diagnostic criteria for FAS, pFAS and ARND will follow the Canadian Diagnostic Guidelines (Chudley et al., 2005).

Method: ACA (con't)



OFC - occipitofrontal circumference

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