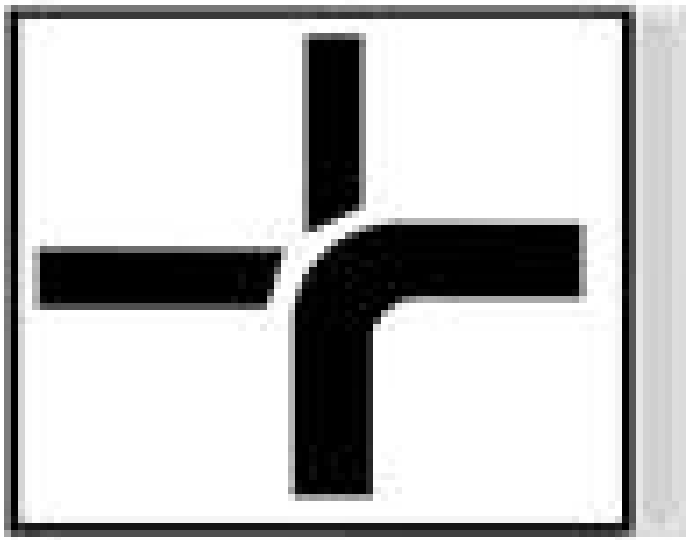
Global Perspective on Epilepsy:

Improving Access to Epilepsy Care

Tarun Dua

World Health Organization

Why Epilepsy is a Priority?



I. Epilepsy: The Burden

- More than 50 million people with epilepsy
- Mortality 3-6 times higher than general population
- Epilepsy contributed 17.43 million DALYs in 2010 (0.7% of the global burden) – IHME estimates 2012
- 85% of the burden in poor, underprivileged and vulnerable
- High economic cost - Cost in Europe estimated as 13.8 billion €

Prevalence: How many people have epilepsy?

Plethora of studies (230 studies)

- Wide variations
  - 2.5 - 57/1,000

Number of people with active epilepsy (independent of location):

- 5 - 10/1,000
- Usually higher in rural areas
- Reports that more people have epilepsy in resource-poor countries in selected or isolated populations

GBD review

More people develop epilepsy in resource-poor countries

Higher Incidence: 49 to 215 per 100 000 in LLMIC

Possible reasons:

- Secondary epilepsy
  - CNS infections and parasites (e.g. neurocysticercosis)
  - Head injury, stroke etc
  - Poor perinatal care

- Social factors
  - Poverty
  - poor sanitation
  - inadequate health delivery systems

Duncan et al, Lancet 2006

Role of mortality

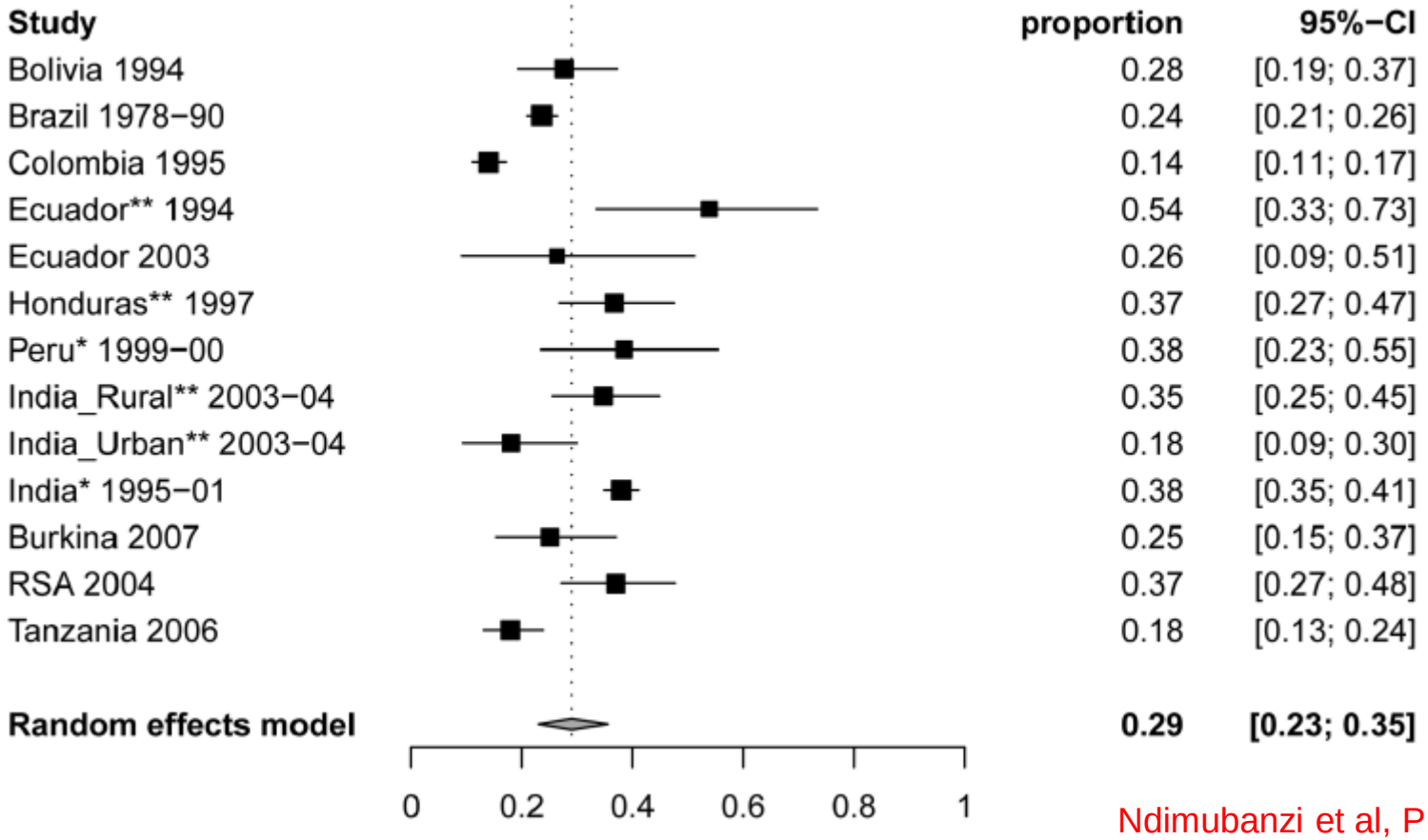
- Premature mortality approx 3 time that of general population in developed countries
- Circumstantial evidence of even higher mortality (6x) from developing countries
- Cause of death
  - Accidents
  - Self-harm/Suicide
  - Status epilepticus
  - SUDEP
  - High psychiatric co-morbidity

Key Points - I

- Epilepsy global burden information available
- Higher epilepsy incidence in resource-poor settings due to risk factors – amenable to prevention?
- Prevention of epilepsy deaths – management of psychiatric comorbidity and lifestyle education?

Swedish data: In epilepsy patients with premature mortality due to external causes, 75·2% had comorbid psychiatric disorders (co-occurring depression (13·0, 10·3–16·6) and substance misuse (22·4, 18·3–27·3)), compared with patients with no epilepsy and no psychiatric comorbidity (Fazel et al, Lancet 2013)

Neurocysticercosis – may be responsible for 29% of epilepsy in endemic countries



Ndimubanzi et al, PLoS 2010

Neurocysticercosis prevention projects

- Project in Peru
- Project in Honduras

Decreasing incidence of NCC in Latin America???

Epilepsy prevention programmes

- Decrease in NCC → Decrease in epilepsy? (some evidence available from Honduras)
- Decrease in road traffic accidents → Decrease in traumatic brain injuries → Decrease in epilepsy incidence?
- Malaria control interventions → Decrease in cerebral malaria → Decrease in epilepsy incidence?
- Improved perinatal care → Decreased birth asphyxia →Decrease in epilepsy incidence?

II. Epilepsy: The hidden burden (Stigma)

- Names
  - “being chosen”
  - “being possessed”
  - “hidden disease”
  - “burning or drowning disease”
  - “shameful disease”
  - “it”

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Epilepsy: the impact

- Children not being able to go to school
- Adults with problems obtaining and retaining employment
- Violations of human rights
  - Social ostracism
  - denial of the right to participate in social activities
  - To marry

Stigma literature review (ILAE)

- Epilepsy stigma well studied (284 studies on factors/frequency/nature of epilepsy stigma)
- 38 studies on stigma tool development
- Only 28 studies on stigma interventions

Key Points - II

- No consensus on measurement of community attitudes/stigma
- Need for well-designed stigma intervention studies
- Role of public awareness/advocacy campaigns

WHAT CAN BE DONE

III. Treatment of epilepsy

- 70% of epilepsy can be successfully treated with antiepileptic medications
- These medications – phenobarbital, phenytoin, carbamazepine, valproic acid are effective, cost-effective and are included in essential medicine list
- Cost of treatment with phenobarbital – as low as 5 USD per person per year
- 23% of burden due to epilepsy is avertable at 50% coverage with standard antiepileptic drugs (Chisholm et al, 2005)

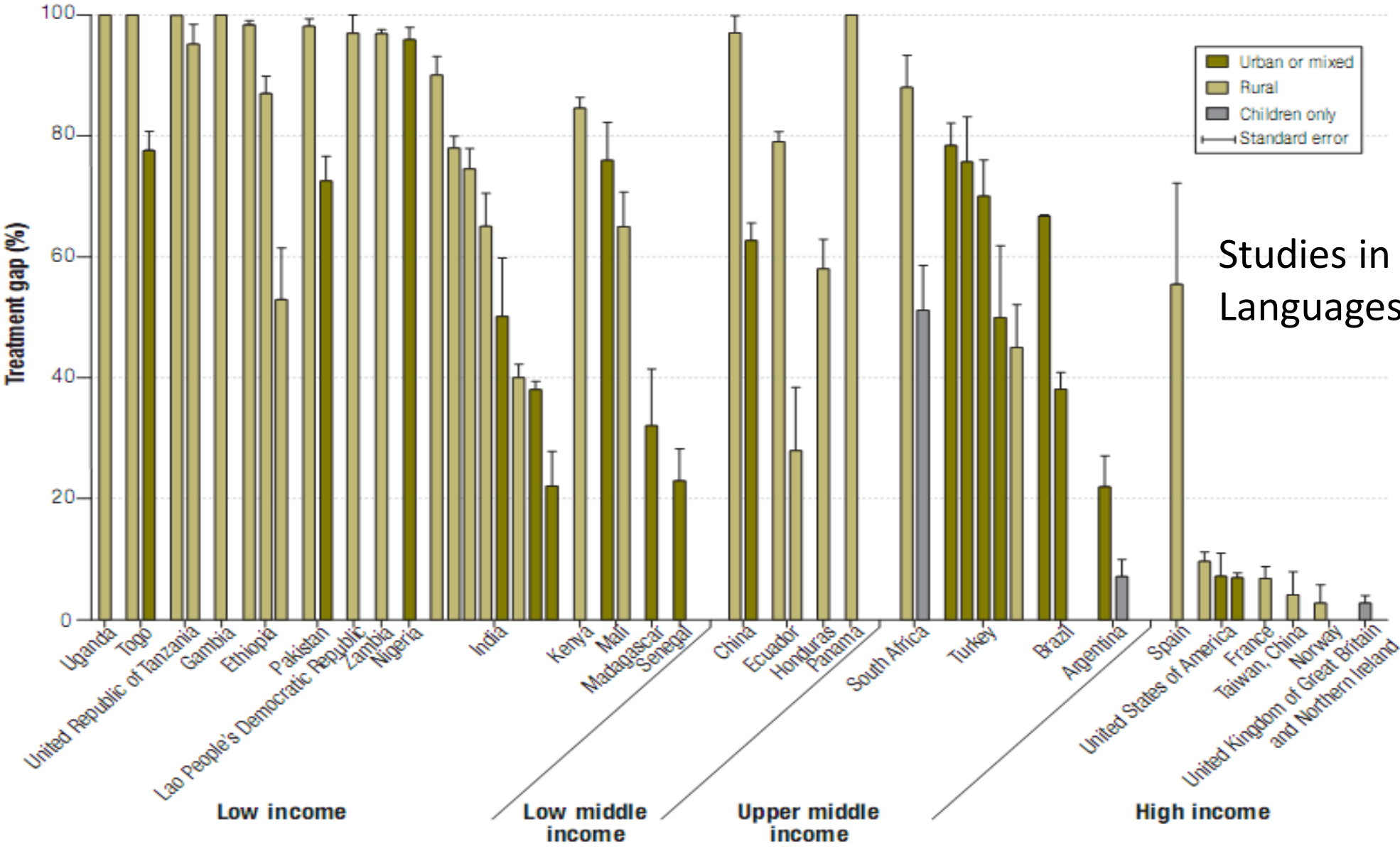
III. Still high treatment gap ?

- Systematic review (2009) – 74 studies
- Treatment gap
  - over 75% in low-income countries
  - over 50% in most lower middle- and upper middle-income countries
  - many high-income countries had gaps of less than 10%
- Treatment gap significantly higher in rural areas (RR: 2.01; 95% CI: 1.40–2.89) and countries with lower World Bank income classification (RR: 1.55; 95% CI: 1.32–1.82)

Meyer et al, Bull WHO, 2010

Global disparities in the epilepsy treatment gap: a systematic review

Ana-Claire Meyer,[a] Tarun Dua,[b] Juliana Ma,[c] Shekhar Saxena[b] & Gretchen Birbeck[d]



Studies in All Languages

Bull World Health Organ 2010;88:260–266

High treatment gap

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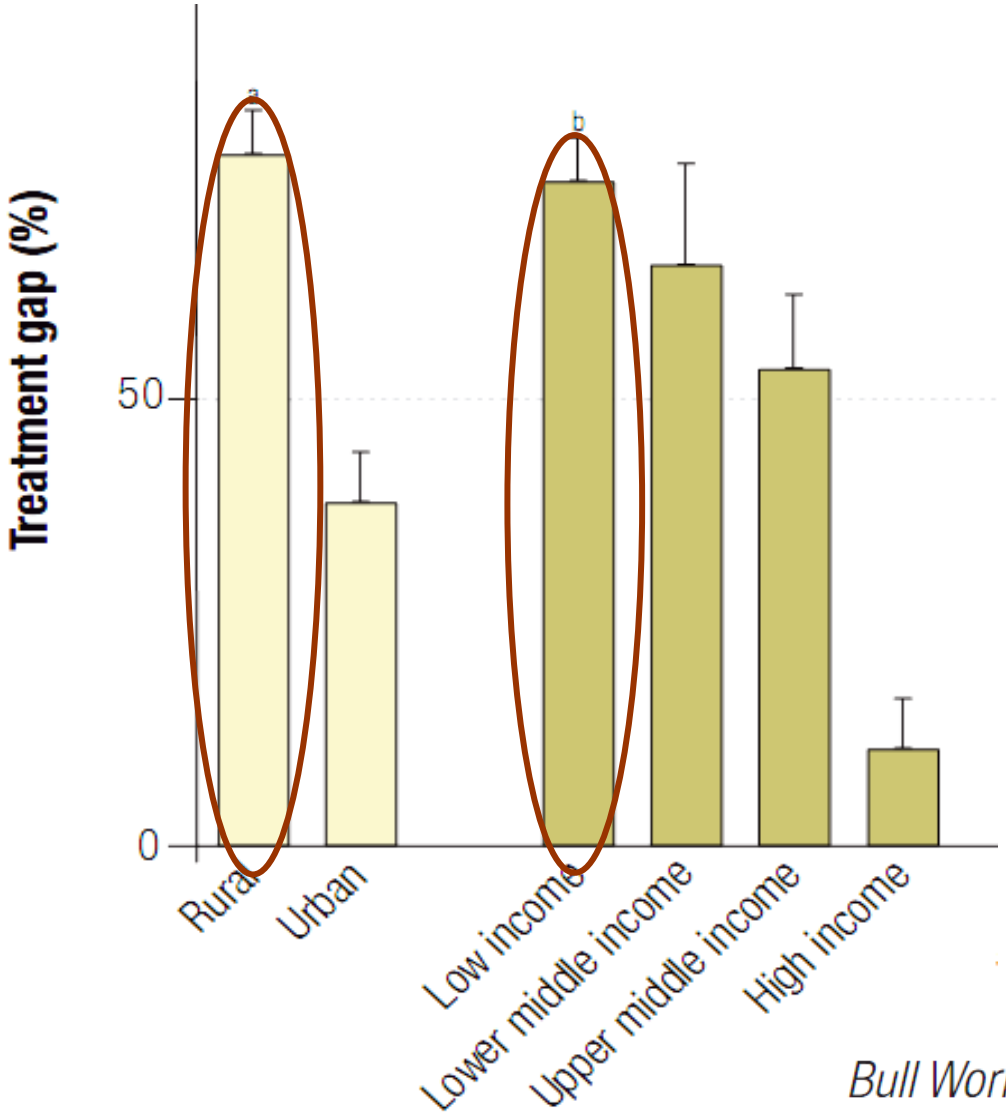


Bull World Health Organ 2010;88:260–266

Why such a high treatment gap?

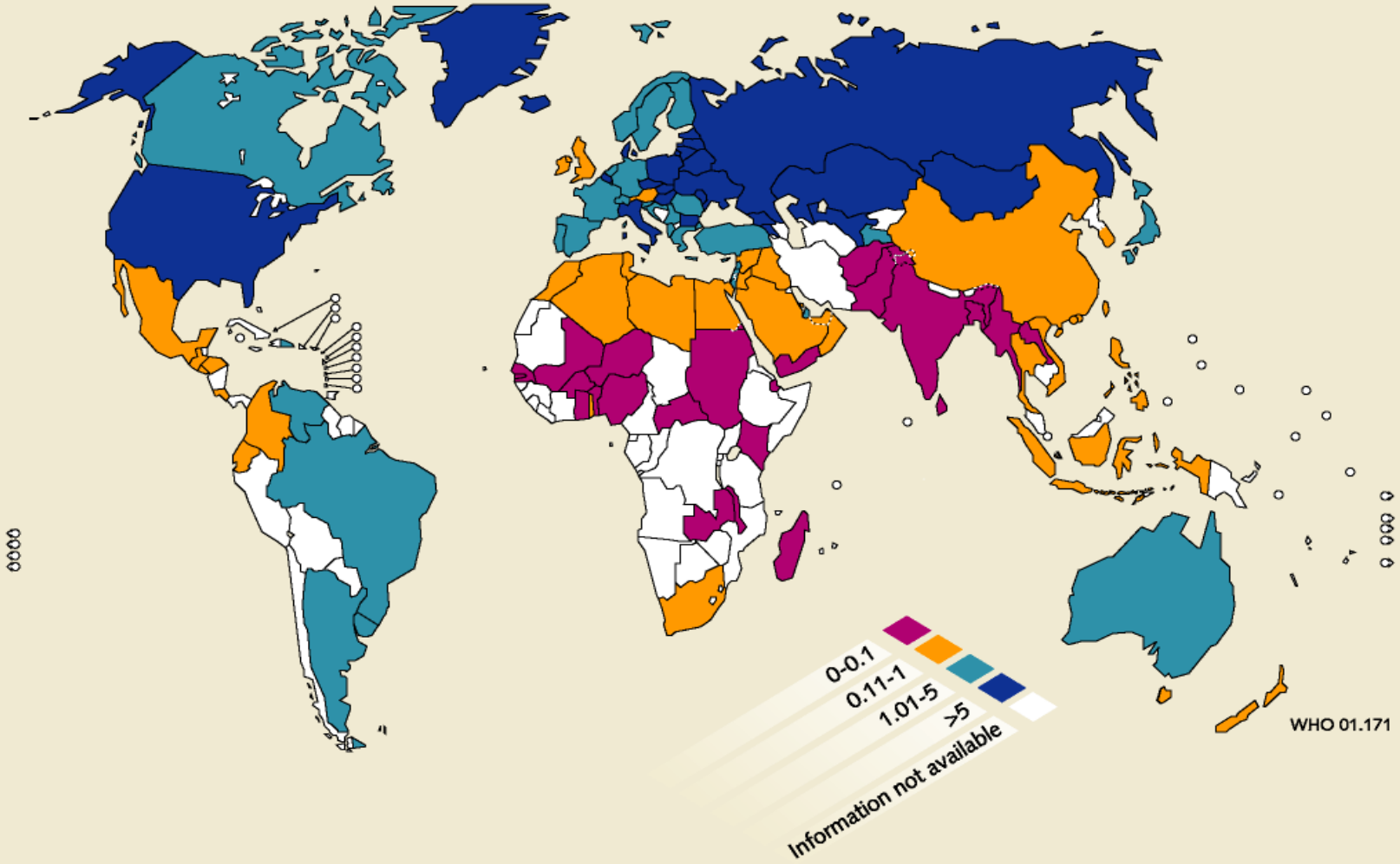
Supply side - Delivery of Health

- Health economics
  - absence of health insurance
- Priorities
  - epilepsy usually not a priority
- Infra-structure
  - shortage of trained health personnel
  - lack of facilities
- Access to medicines
  - High cost and unavailability

Number of neurologists per 100 000 population

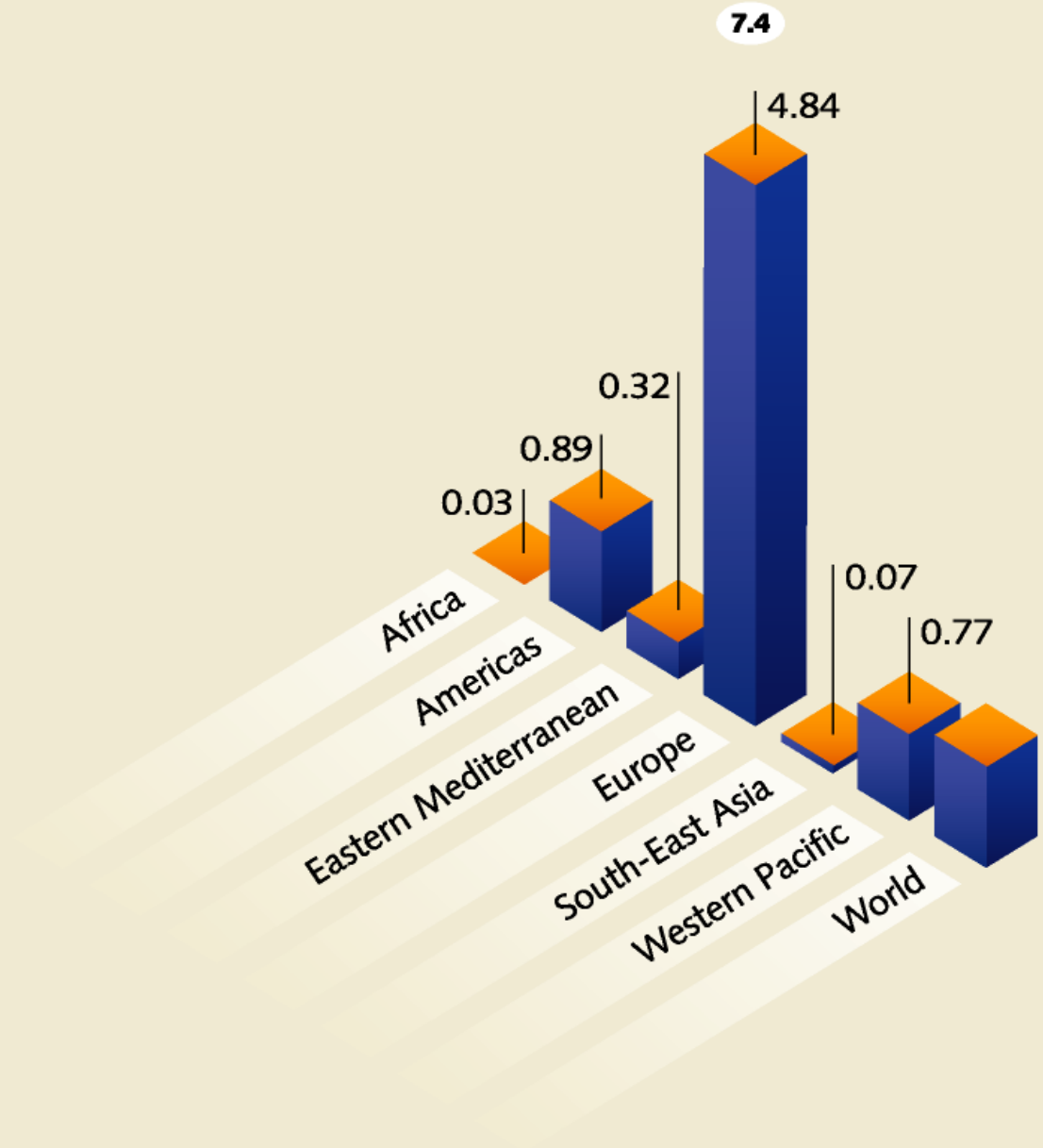
N=106

7.1



Median number of neurologists per 100 000 population in each WHO region and the world

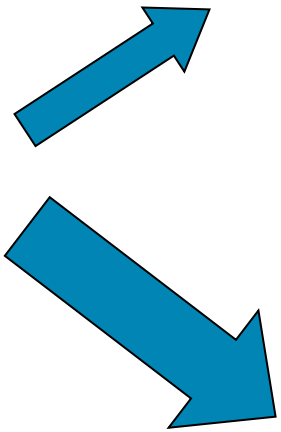
N=106



Neurologists and population in Africa: projected trends

Currently

- 425 neurologists
- 1 per 3 million people



In 10 years time

(current trends)

- 600 neurologists
- 1 per 3 million people

(capacity doubled)

- 1,200 neurologists
- 1 per 1.5 million people

Better training for primary care providers essential

National Essential Medicine Lists and AEDs

- Comparative analysis of 109 NEML of countries (2012)
- AED presence on NEML
  - Phenobarbital included in 96% of the responding countries
  - Carbamazepine in 95%
  - Phenytoin in 83%
  - Valproic acid in 92%
- All strengths and formulations of AEDs included as recommended by the WHO EML
  - Phenobarbital in 12%, Carbamazepine in 5%, Phenytoin in 3%, and Valproic acid in 11%.

Draft publication being prepared

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Availability, price and affordability of antiepileptic medicines in 46 countries

- **Availability**
  - Generic essential AEDs in the public sector less than 50%
- **Price for generic carbamazepine and phenytoin**
  - Public sector patient prices were 4.95 and 17.50 times higher than international reference prices
  - Private sector patient prices were 11.27 and 24.77 times higher
  - Originator brand prices were about 30 times higher.
  - Highest prices observed in the lowest income countries.
- **Affordability**
  - The lowest-paid government worker would need 1-2.6 days wages to purchase a month's supply of phenytoin, while carbamazepine would cost 2.7-16.2 days wages

Cameron et al, Epilepsia 2012

Demand side - Health Seeking Behaviour

- Patient's beliefs
  - Cause of illness
  - Role of biomedical treatment
  - Traditional/faith healers
- Logistics
  - Expense
  - Distance from facilities

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What should be done?

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Increase access to epilepsy treatment worldwide - III

- Raise epilepsy priority in the national health agendas
- Involve non-specialist providers in delivering epilepsy care and services
- Integrate epilepsy management in primary health care system
- Increase availability of essential antiepileptic medications
- Promote public awareness and education about epilepsy

"OUT OF THE SHADOWS"

A Global Campaign against Epilepsy

The Partners:

The International League Against Epilepsy (ILAE)

The International Bureau for Epilepsy (IBE)

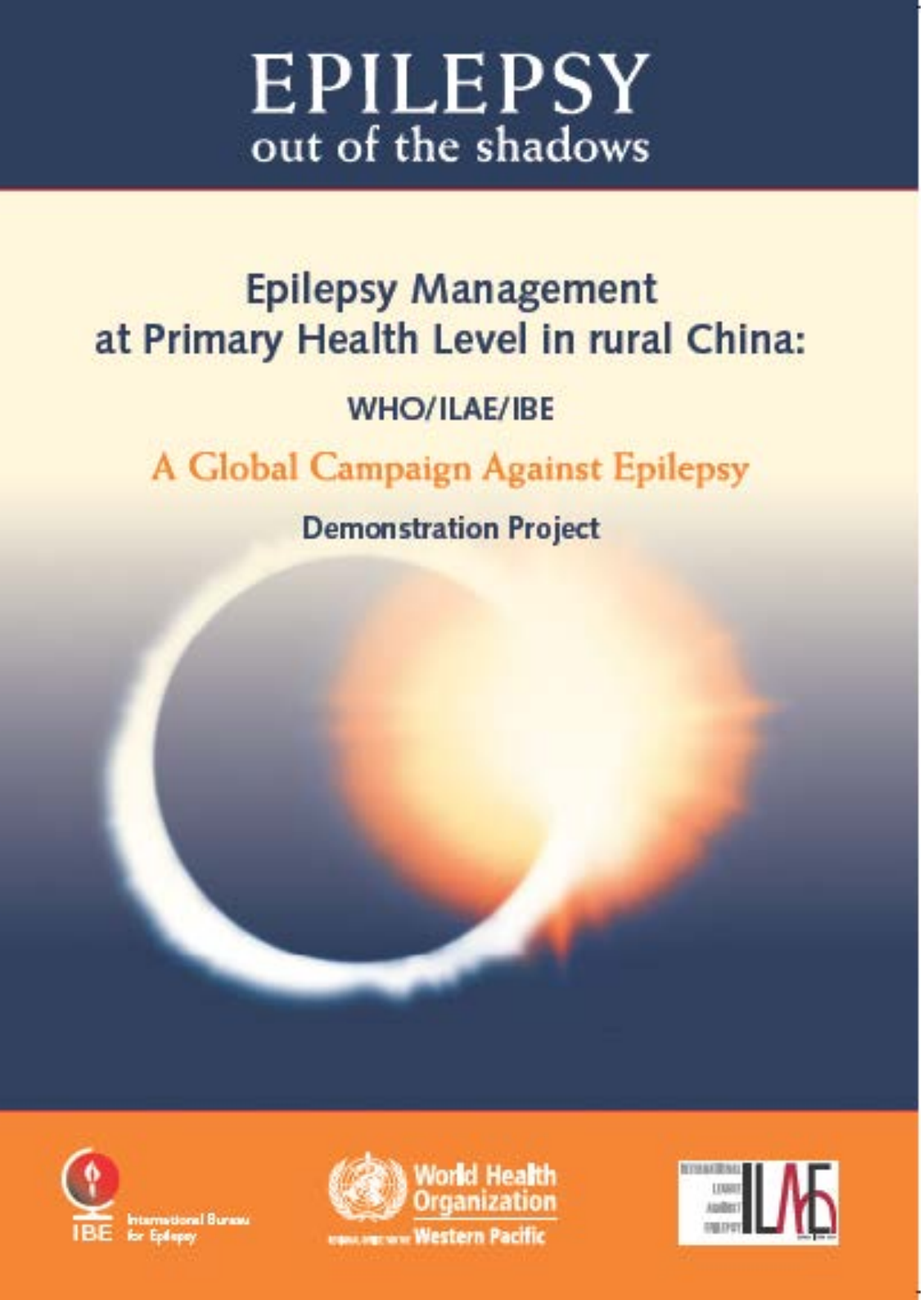
World Health Organization (WHO)

Awareness and advocacy

- Regional Conferences
- Regional Reports
- Atlas: epilepsy care in the world

Care Models

- ICEBERG
  - Kenya, Pakistan, Ecuador
- Country specific examples
  - Tanzania, Malawi, Ethiopia, Kenya, India, Senegal
- SANCHAR-AROD
  - 24 Parganas
- Global Campaign Demo Projects
  - E.g. China, Senegal, Brazil, Georgia



Epilepsy demonstration project: example of China

Project

- To test the feasibility of diagnosis and treatment of epilepsy at the primary health care level

- The long- term goal: To integrate epilepsy management into the existing primary health delivery system of the People's Republic of China

- 6 provinces and 4 million population

China Project: Conclusions

- Trained town clinic physicians and rural doctors can diagnose and treat people with epilepsy
- Reduction in treatment gap by 13% (statistical significant ↓)
- The methods and the experiences obtained are suitable to extend in rural areas of China, as well as in some other developing countries

Scaling up: China National Epilepsy Project

- Government Support
- Free Medical Care
- Public Education

Ministry of Health, China

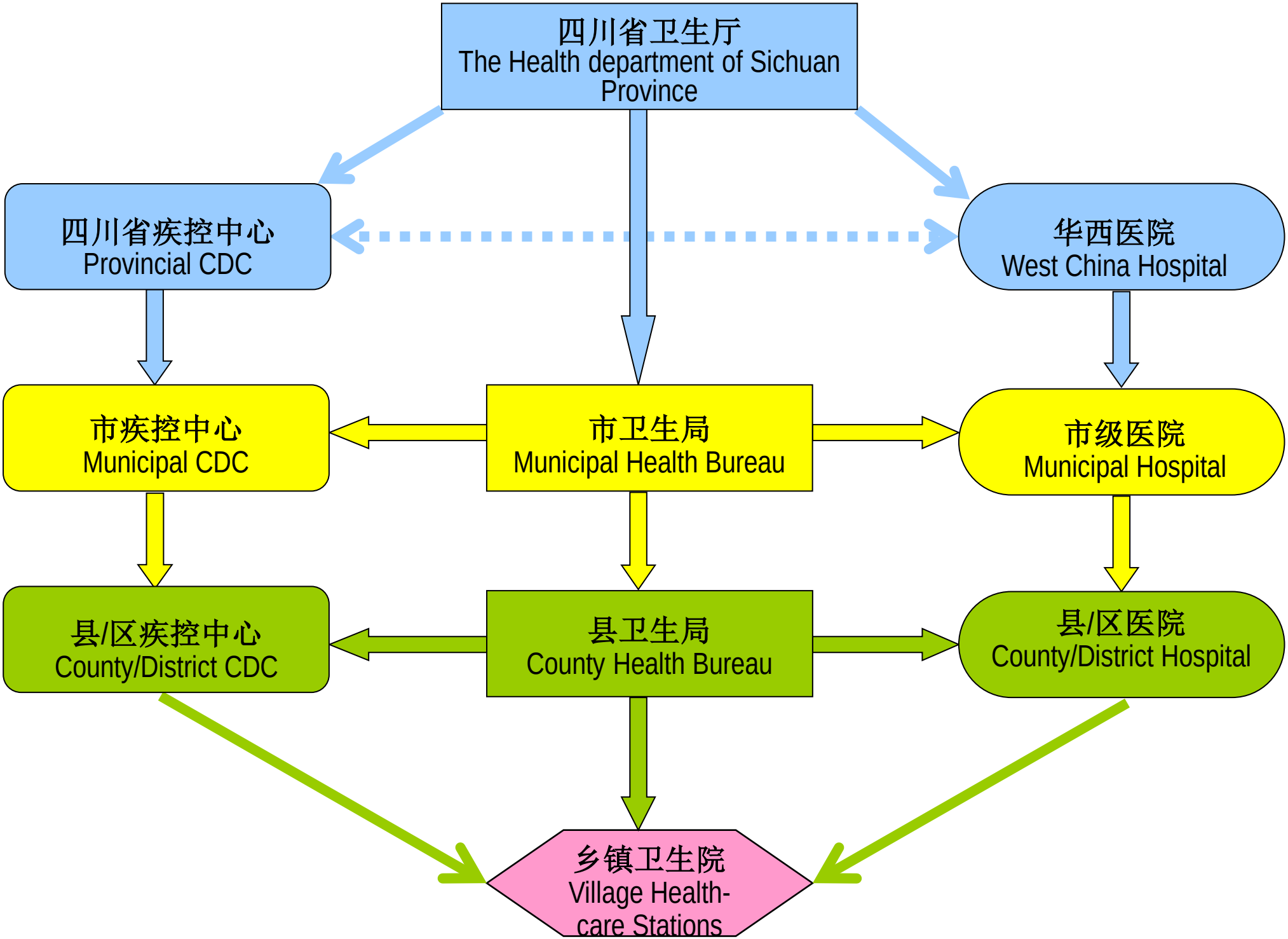
China Association Against Epilepsy

2005~2009

The results of the National Epilepsy Project

- Established administration and professional epilepsy teams in **15** provinces (**79** counties)

- Popularization of knowledge of epilepsy in project areas (over **44 million** population)


四川省卫生厅
The Health department of Sichuan Province
四川省疾控中心
Provincial CDC
华西医院
West China Hospital
市疾控中心
Municipal CDC
市卫生局
Municipal Health Bureau
市级医院
Municipal Hospital
县/区疾控中心
County/District CDC
县卫生局
County Health Bureau
县/区医院
County/District Hospital
乡镇卫生院
Village Health-care Stations

Other initiatives

- In rural Kenya, sensitisation of the community and setting up an epilepsy clinic reduced the treatment gap over a 5-year period from 74% to 62%

- In India, 70% of enrolled patients were still attending the clinics 12 months after initiation of training programmes of volunteer health-care workers, traditional practitioners and clinicians; awareness campaign programmes; and diagnosis, treatment, and monthly follow-up with free AEDs

Integration into Mental Health or Non-Communicable Diseases?

Mental Health ?

- In many countries, epilepsy included as part of mental health programme
- Epilepsy managed by community psychiatric nurses – e.g. Ghana
- Many more psychiatrists than neurologists – e.g. Panama (only 12 neurologists for 3 million population)
- Neurologists often not interested in public health aspects of neurological disorders
- Stigma and treatment gap causes similar
- Substantial psychiatric co-morbidity
- Adoption of Comprehensive Mental Health Action Plan
- PAHO – Regional Strategy on Epilepsy

NCDs?

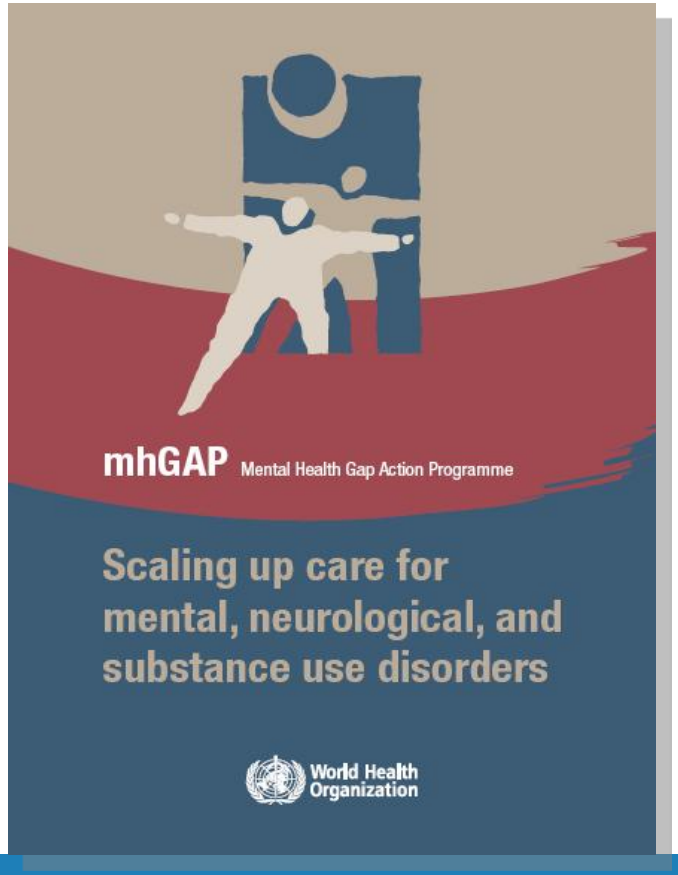
- NCDs high on political agenda – UN high level political resolution
- Issues of access to medicines similar
- Similar strategies being applied for improving care of NCDs

WHO's Mental Health Gap Action Programme (mhGAP)

. Scaling up Care: mhGAP

mental health Gap Action Programme

Scaling up care for mental, neurological and substance use disorders



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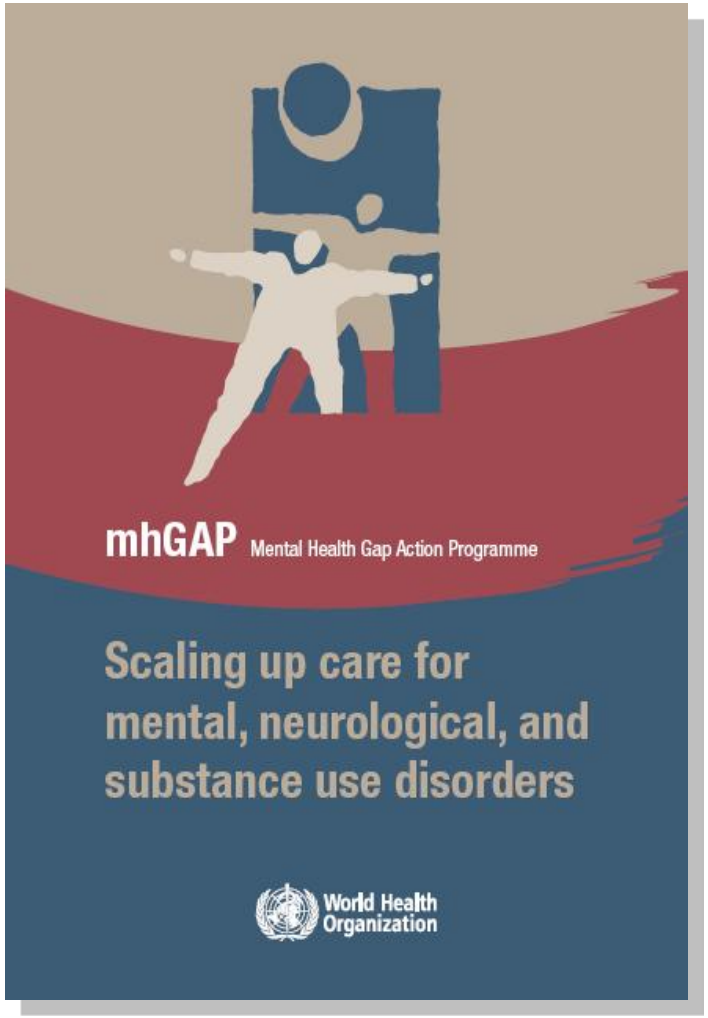
Setting priorities



Priority conditions:

- Depression
- Suicide prevention
- Psychoses
- Child and adolescent mental disorders
- Epilepsy
- Dementia
- Disorders due to use of alcohol
- Disorders due to illicit drug use

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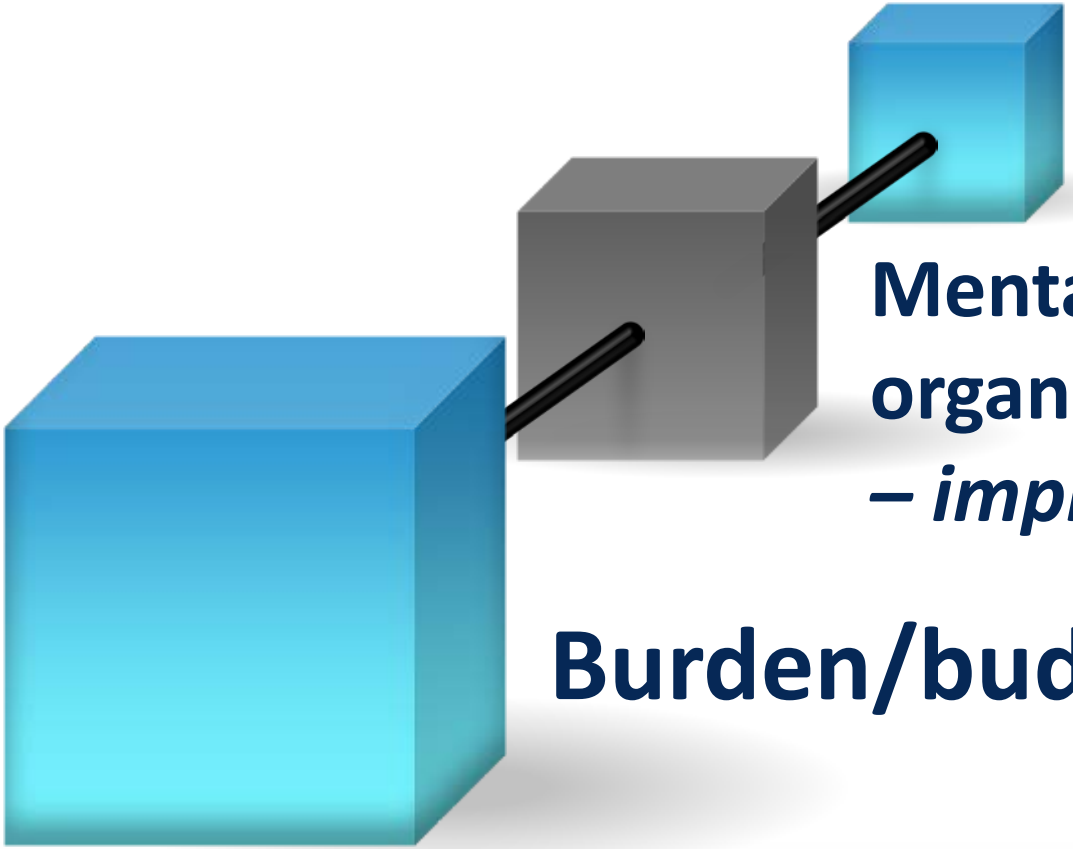
The underlying logic of mhGAP

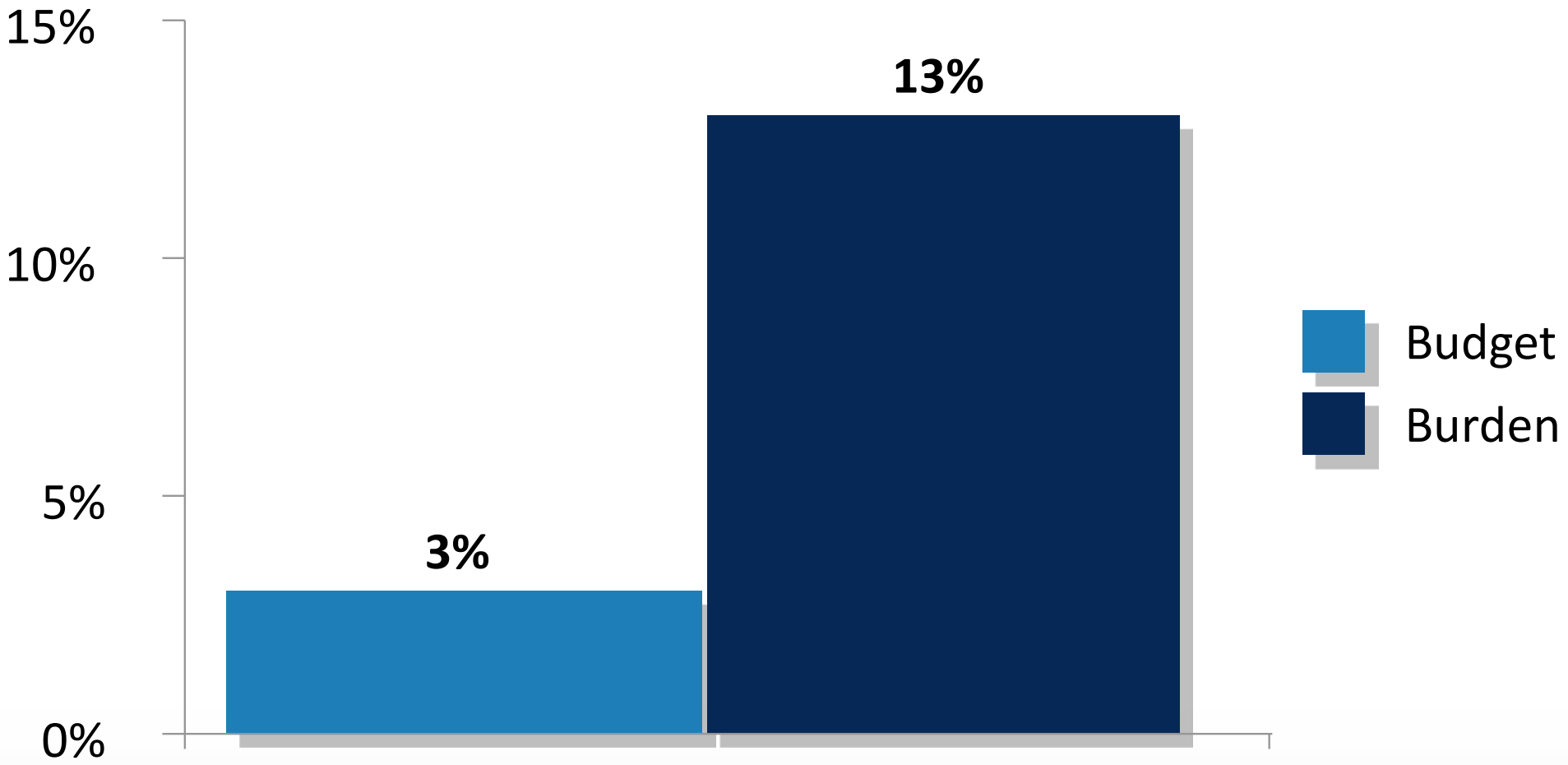


Human rights abuses are to be stopped

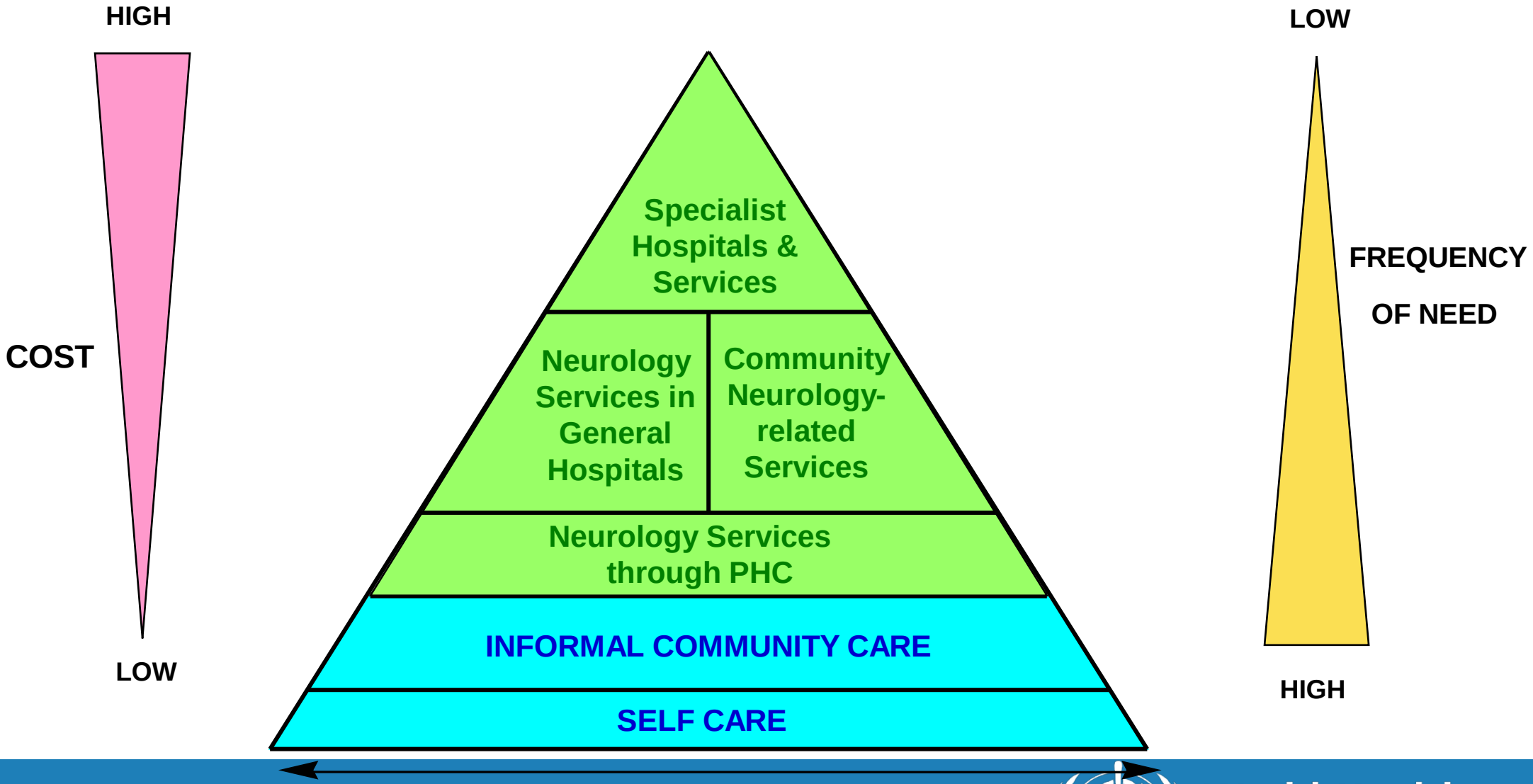
Mental health services to be organized rationally
– improvement in coverage

Burden/budget gap to be reduced

Burden/budget gap to be reduced



Neurology Services (WHO, 2003)



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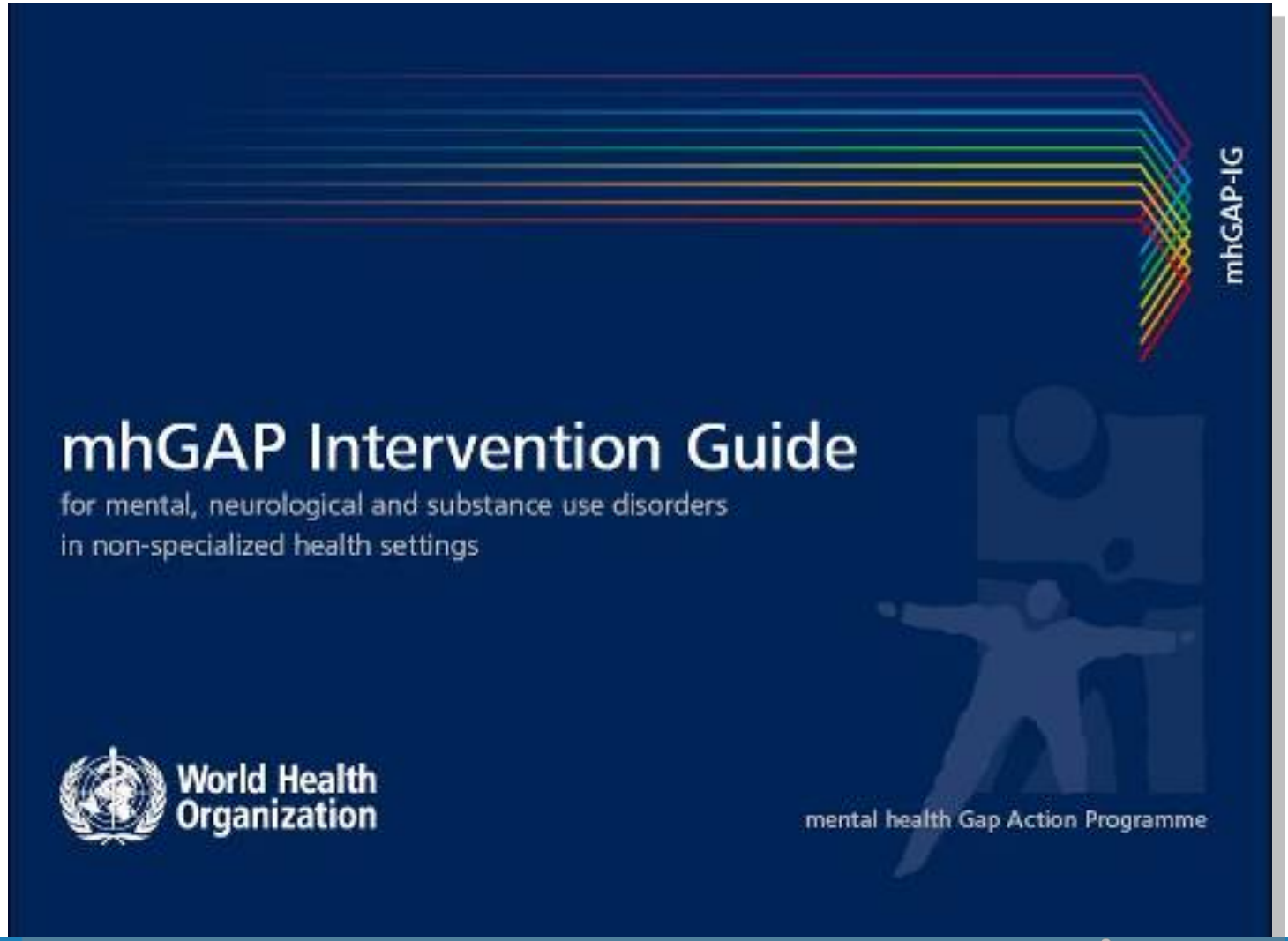
mhGAP Intervention Guide:

Evidence based interventions for priority conditions in non-specialized health care settings



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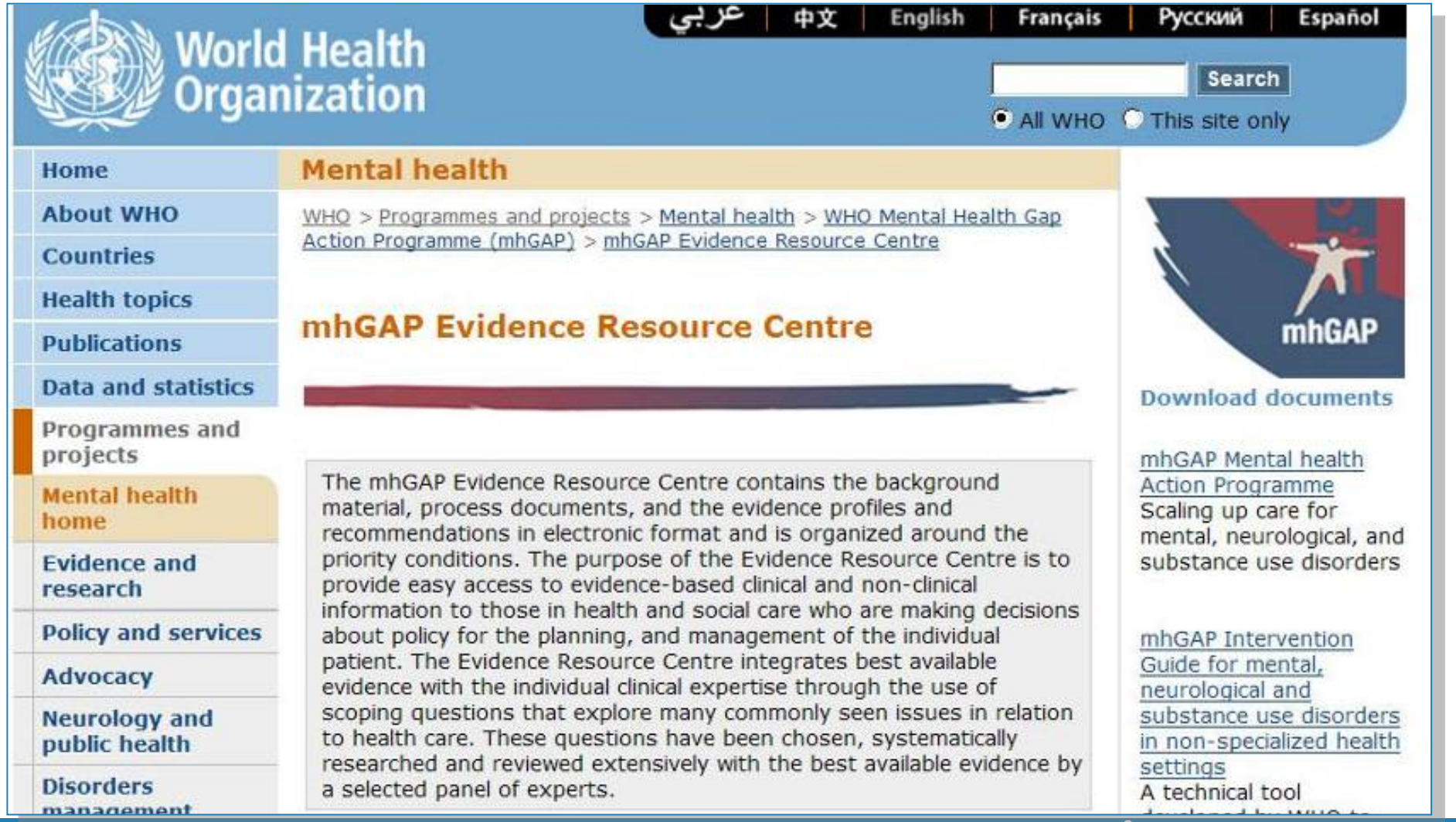
GI-mhGAP
Guide d'intervention mhGAP
pour lutter contre les troubles mentaux, neurologiques et liés à l'utilisation de substances psychoactives dans les structures de soins non spécialisées
Organisation mondiale de la Santé
Programme d'action Combler les lacunes en santé mentale


GI-mhGAP
Guía de Intervención mhGAP
para los trastornos mentales, neurológicos y por uso de sustancias en el nivel de atención de la salud no especializada
Organización Mundial de la Salud
Programa de acción mundial para superar las brechas en salud mental

Evidence based



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Epilepsy / Seizures

EPI 1

Assessment and Management Guide

If no acute cause

3. Has the person had at least 2 convulsive seizures in the last year on 2 different days?

Ask about:
- Severity:
  - How often do they occur?
  - How many did they have in the last year?
  - When was the last episode?
- Possible etiology of the epilepsy (any history of birth asphyxia or trauma, head injury, infection of the brain, family history of seizures)

NO

If there is no clear cause and the person had a single convulsive seizure

Not epilepsy
- Maintenance of antiepileptic drugs is not required.
- Follow up after 3 months. If there are additional abnormal movements suggestive of a seizure, assess for possible epilepsy.

YES

If yes,
consider epilepsy

- Initiate antiepileptic drug (F) » **EPI 2.1**; either phenobarbital, phenytoin, carbamazepine or valproate. » **EPI 2.3**
- Educate about condition, lifestyle and safety issues, and importance of adherence and regular follow-up. » **EPI 3.1**
- Follow up regularly. » **EPI 2.2**

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mhGAP Country Implementation

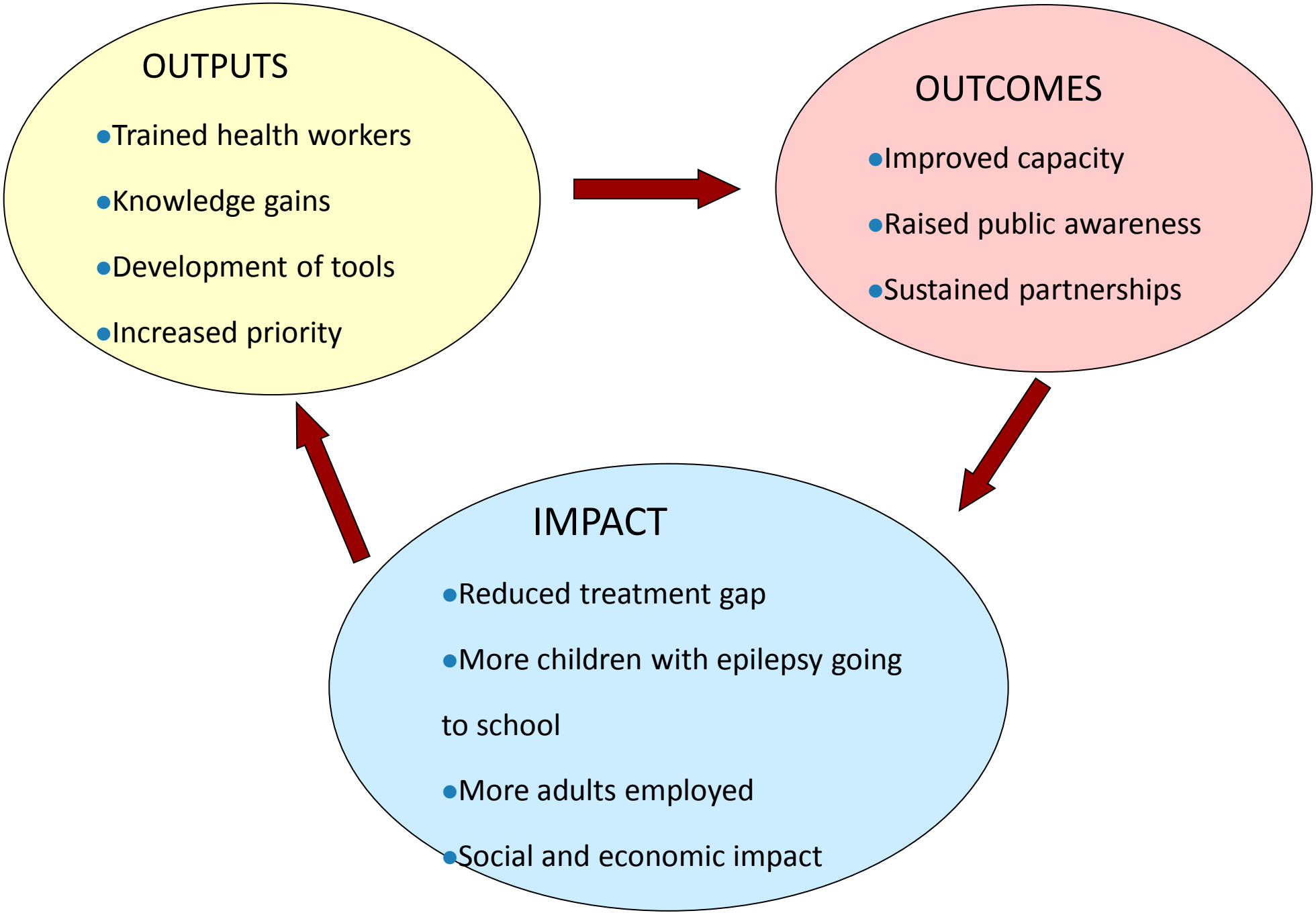
- Ethiopia, Nigeria, Uganda
- Jordan
- Panama, Belize
- Implementation by PAHO in other countries in the region
- Implementation by national or international partners in many countries (e.g. CBM)
- Research funding for multiple countries
- Epilepsy projects in Ghana, Viet Nam, Myanmar and Mozambique

Target beneficiaries

mhGAP strategy

- Non-specialist health personnel within first and second level care
- Involvement of nurses and community health workers, as applicable
- Under supervision and support and educative role of specialists (mental health professionals, neurologists, paediatricians)
- Strengthening of health systems
  - Referral
  - Supervision
  - Supply of medicines
  - Traditional healers/faith healers where applicable
- Involvement of self help/user groups, NGOs
- Attention to undergraduate and postgraduate curriculum

Evaluation framework



EPILEPSY
OUT OF THE SHADOWS

- EPILEPSY is the commonest serious brain disorder in every country.
- It is misunderstood, feared, hidden, stigmatised.
- 60-90% of people with EPILEPSY in developing countries do not receive appropriate treatment.
- There are 50 million people with EPILEPSY in the world and 85% of them are living in developing countries.

- EPILEPSY is a treatable brain disorder.
- It is not a supernatural, mental or psychological disorder.
- 70-80% of people with EPILEPSY could lead normal lives if properly treated.
- Please help bring EPILEPSY "Out of the Shadows".