Lessons learned from 25 years of experience in follow-up of children at risk for disabilities: **The Colombian Kangaroo Mother Care Program**

XII INTERNATIONAL CONFERENCE ON KANGAROO MOTHER CARE

November, 14th to 17th 2018, Bogota - COLOMBIA

N. Charpak, Pediatrician and Director of the

Kangaroo Foundation

of Colombia

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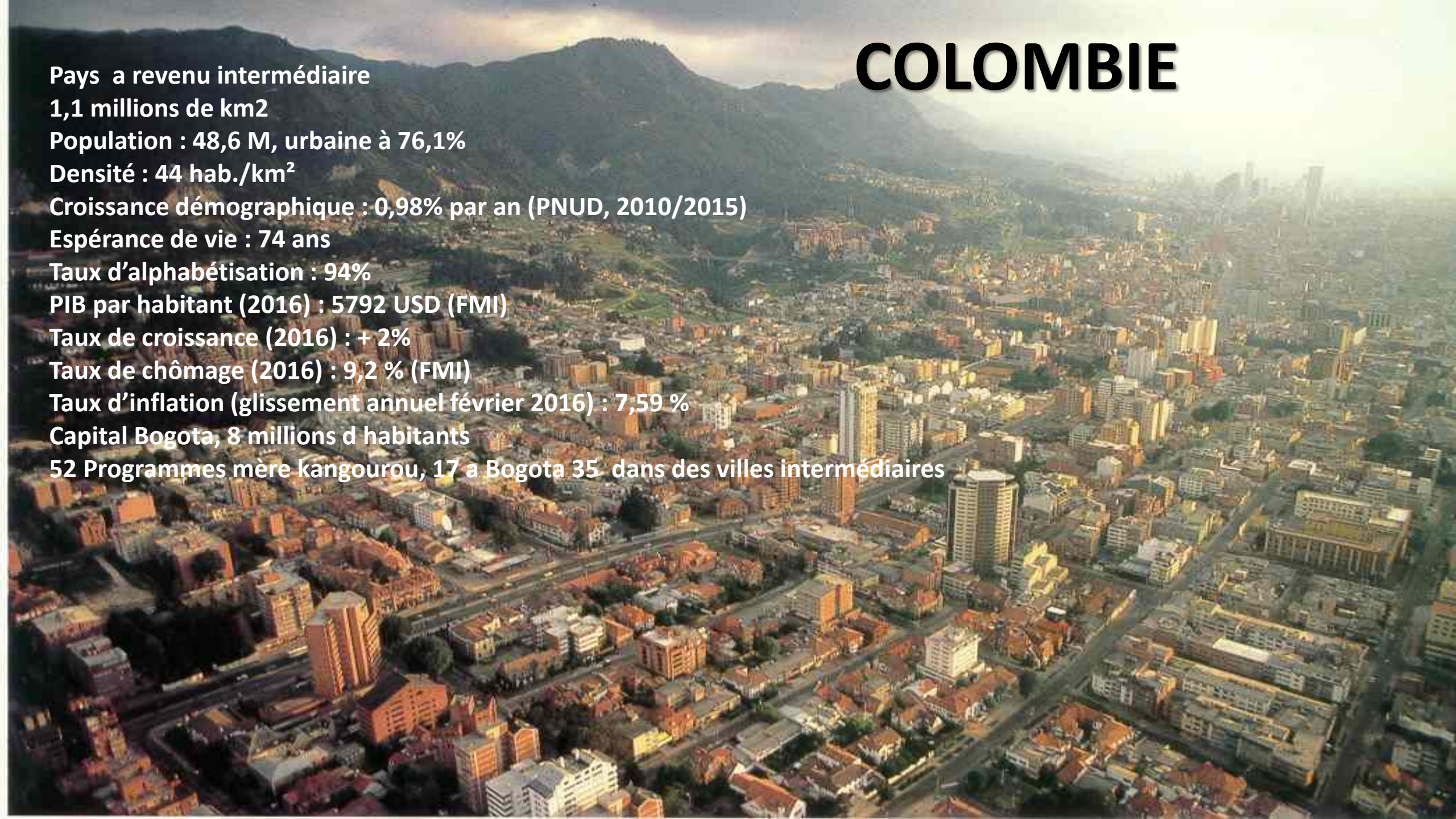
COLOMBIE



Pays a revenu intermédiaire
1,1 millions de km2
Population : 48,6 M, urbaine à 76,1%
Densité : 44 hab./km²
Croissance démographique : 0,98% par an (PNUD, 2010/2015)
Espérance de vie : 74 ans
Taux d'alphabétisation : 94%
PIB par habitant (2016) : 5792 USD (FMI)
Taux de croissance (2016) : + 2%
Taux de chômage (2016) : 9,2 % (FMI)
Taux d'inflation (glissement annuel février 2016) : 7,59 %
Capital Bogota, 8 millions d habitants
52 Programmes mère kangourou, 17 a Bogota 35 dans des villes intermédiaires

KMC: the perfect nurturing care for the premature/LBWI (1999)

NURTURING THE PREMATURE INFANT

Developmental Interventions in the Neonatal Intensive Care Nursery

EDWARD GOLDSON, M. D.

Oxford University Press

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KANGAROO CARE OF THE PREMATURE INFANT

GENE CRANSTON ANDERSON

At birth, both full-term and preterm infants enter a foreign environment that lacks the skin-to-skin contact and close containment of extremities in the womb. This shock can be ameliorated by placing infants skin-to-skin with their mothers as soon as possible postbirth. When they are with their mothers, infants are in

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The Lancet Series *Advancing Early Childhood Development: from Science to Scale (2016)*, chaired by WHO and UNICEF brought together state-of-the-art evidence highlighting that the time is right to strengthen programming for early childhood development. The series emphasized that 'nurturing care'– is the foundation for child development. The key messages are:

- The beginning of a child's life (pregnancy to age 3)is a period of special sensitivity for child development;
- The most formative experience of young children come from nurturing care received from parents and other caregivers;
- To create an enabling environment for nurturing care, policies and services are essential

The answer: Implementation of a KMC program as a cost effective Unit of Care for the first year of life of the premature and LBWI

What is a KMC program (KMCP)?

The terms *program*, *intervention* and *method* are vaguely used in the scientific literature (and among health care professionals) resulting in some confusion.

- **The Kangaroo Mother Care Method** (KMCM) is a standardized and protocol-based care system for preterm and/or low birth weight infants, based on skin-to-skin contact between the preterm baby and the mother, which aims at empowering the mother (parents or caregivers) to gradually transfer the skills and responsibility to become the primary caregiver for their child, meeting each and every physical and emotional need.
- **The intervention (Kangaroo Mother Care Intervention)** consists of a series of items that are applied thoroughly and systematically, following a certain method: the kangaroo mother care method.
- **The Kangaroo Mother Care Program** is the group of activities aimed at implementing a specific health care *intervention*; in this case the kangaroo mother intervention, with an adequately trained and organized health care team within a specific administrative and physical structure.

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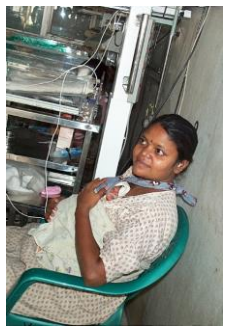

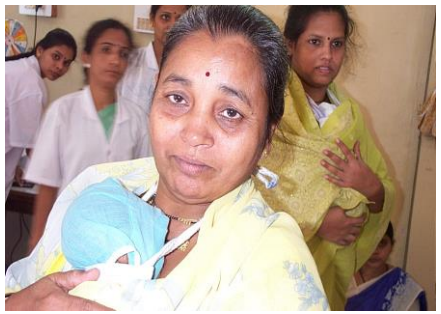

Ambulatory Kangaroo Mother Care Program, very similar to a ECD program for the first year of corrected age

The Kangaroo Mother Care program includes a follow up program in 2 steps:

1. From discharge from the neonatal unit up to 40 weeks of gestational age.

2. From term up to one year of corrected age

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OUTPATIENT FOLLOW UP IN THE KMCP

KMC Follow up program includes the 6 following aspects:

1. **Outpatient Kangaroo adaptation**: re-enforcement of the training in kangaroo position and the kangaroo nutrition for families trained in KMC in the hospital and then discharge to home in kangaroo position and training for new parents joining the KMC program after discharge from different units not implementing KMC.

2. **Regular monitoring** of somatic growth, neurological and psychomotor development, as compared to referral standards during the first year of life.

3. **Early identification, treatment, and rehabilitation** of any disorders in preterm and/or LBW infants, which may include the intervention of specialists.

1. **Support and counseling strategies for the family**.

2. **Quality monitoring of the kangaroo clinical practice**

3. **Active immunization**.

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Early discharge from the Neonatal Unit to the KMCP

Child's eligibility criteria for discharge(6)

Mother's eligibility criteria for discharge(6)

Family's discharge eligibility criteria (6)

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Physical structure of a KMCP

1. Outpatient kangaroo follow up activities are usually organized daily in premises staffed with a multi-disciplinary team, including pediatricians, nurses, and psychologists trained in KMC.
2. Ideally, this place is located in a hospital where there is a Neonatal Unit equipped with human and technological resources in case of an emergency.
3. When necessary, other health professionals join the team, such as a social worker , nutritionists, physiotherapists, ophthalmologists, optometrists, and orthophonists.
4. Each child is assessed individually and each family receives personalized recommendations; yet, at the same time, the entire group is taught about KMC procedures and benefits.
5. The open (group) consultation is facilitated by a team of health care personnel working together and using multimodal communication techniques, resulting in better adherence to the program by the parents.
6. This methodology also facilitates the collective learning processes and reinforces the mother's knowledge when she repeatedly hears the same advice. Parents, while waiting, can also listen to the problems of other parents and exchange experiences and difficulties.
7. This "group consultation" also decreases the parents' anxiety. The presence and availability of a psychologist supports parents in cases of depression, insecurity, or vulnerability.
8. The commitment to attend the daily consultations at the beginning of the outpatient KMC Program is demanding on parents, and in a way is similar to the daily visits they did when the child was hospitalized, creating a link between neonatal unit and home care.

Assessment of the newborn when first admitted to an outpatient KMC

1. The gestational age at birth is determined according to the Lubchenco's o Fenton classification tables.
2. The anthropometric parameters are assessed (weight, height, head perimeter)
3. A full clinical assessment is conducted (from head to toes)
4. Outpatient KMC adaptation is reinforced or initiated as necessary.
5. Brain sonography and ophthalmologic screenings are requested if necessary.
5. Routine and specific drugs are prescribed.
7. The need for oxygen is assessed.
8. The need for family support is assessed and provided

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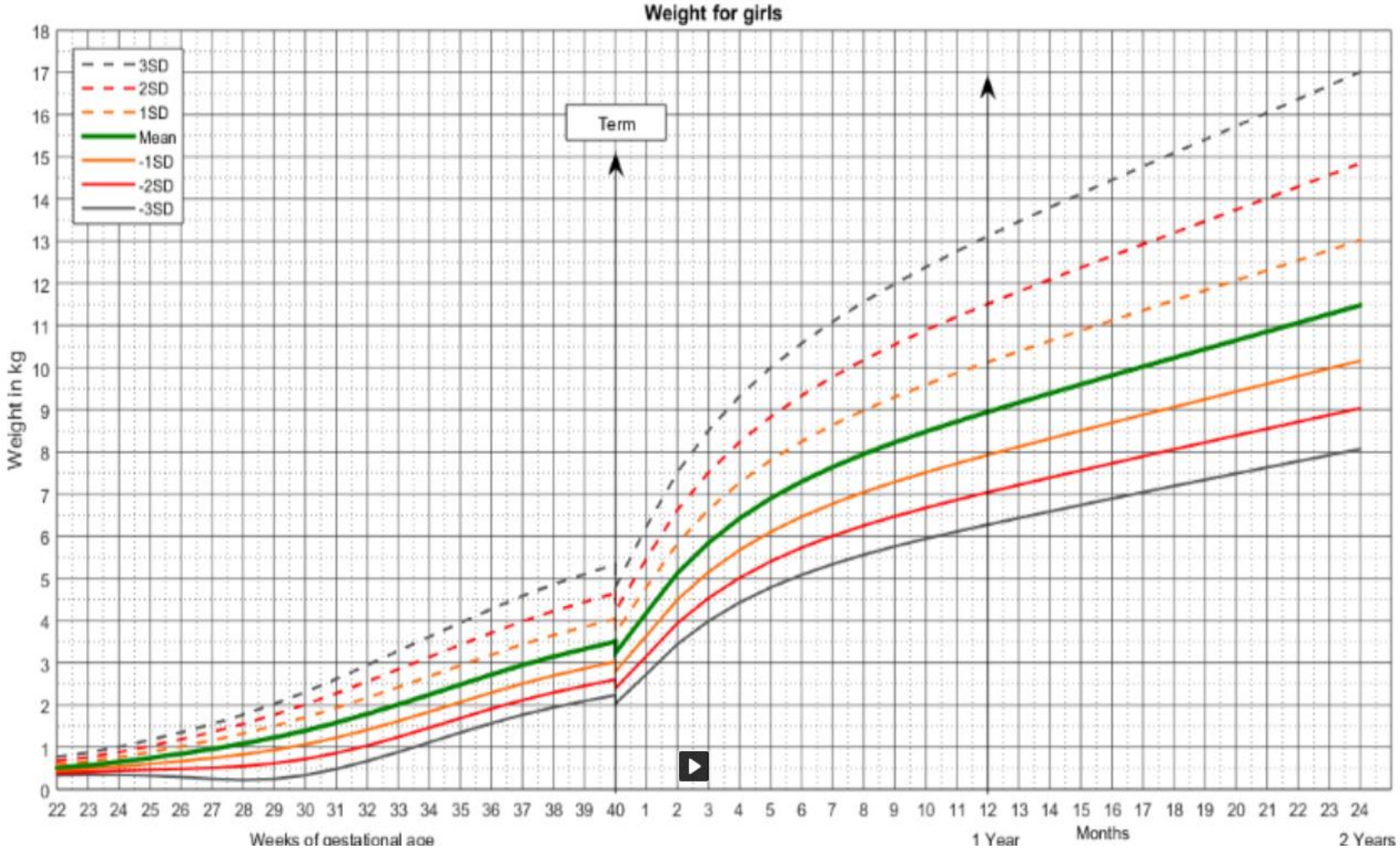

Assessment of the newborn when admitted to an outpatient KMC (IV)

Height for age (H/A)

Cut-off point (Standard deviation or Percentile)	Denomination
< 2	Below length for age or stunting.
≥ - 2 a < - 1	At risk for below length
≥ - 1	Adequate length

Weight for age (W/A)

Cut-off point (Standard deviation or percentile)	Denomination
< - 3	Very low weight for age or severe chronic malnutrition.
< - 2	Low weight for age or chronic malnutrition.
≥ - 2 a < - 1	At risk for low weight for age.
≥ - 1 a < - 1	Adequate weight for age.

Head circumference (HP/A)

Cut-off point (Standard deviation or percentile)	Denomination
< - 2	Risk factor for neurodevelopment
≥ - 2 a < 2	Normal
> 2	Eventually Risk factor for neurodevelopment

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Routine Kangaroo follow up, up to 40 weeks of gestational age and a weight of 2500g

Daily kangaroo follow up is done until the child is 40 weeks of gestational age and reaches 2500 g.

- These visits can be conducted in outpatient care or while the child is in a KMC ward.
- Mothers who have already returned home or who are staying at a temporary home must participate to the Kangaroo Mother Program outpatient consultation.




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Activities during follow up visit up to 40 weeks

Daily kangaroo follow up is done until the child is thriving well then weekly up to 40 weeks of gestational age and reaches 2500 g.

a) Careful and complete clinical assessment

b) Regular monitoring of the somatic growth (weight gain around 15-20 g/kg/day)

c) Strategies in case of insufficient weight gain

d) Advice on child care for “kangaroo infant” at home

e) Duration of the kangaroo position

f) Neurological assessment at 40 weeks of gestational age using axial tone (Dr. Amiel Tison)

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High risk follow up of the preterm and / or LBW infants from 40 weeks up to one year corrected age

Every high risk child must be followed until the first year of corrected age (counting from the moment he reaches 40 weeks) for adequate monitoring of somatic growth and early detection of audition, ophthalmological, and neurological sequel.

- Physical examination

- Monitoring somatic growth

- Complementary feeding:
  - The best way to feed a child from birth to at least 4 months of age is to breastfeed exclusively, and ideally until 6 months if he is thriving well with exclusive breastfeeding.
  - Mothers should breastfeed children at this age as often as the child wants, day and night. This will be at least 8 times in 24 hours in the case of preterm or LBW infant
  - At some time between the ages of 4 and 6 months, some children begin to need foods in addition to breast milk. These foods are often called complementary or weaning foods because they complement breast milk.
  - By 6 months of age, all children should receive thick, nutritious, complementary foods.
  - From age 6 months up to 12 months, gradually increase the amount of complementary foods given.

High risk follow up of the preterm and / or LBW infants from 40 weeks up to one year corrected age (V)

The INFANIB screening or Infant neurological battery test

- The Infant neurological international battery, INFANIB, is a diagnostic/screening method used to identify children with neuromotor anomalies during the first year of life.

- INFANIB is used in children older than 40 weeks and is useful for conducting a “diagnostic screening” of the systematic monitoring of the preterm and LBW population of the Kangaroo Mother Program.

- Evaluates global motor development, tone and archaic reflexes, allowing clinicians to detect multiple neurological alterations such as hypotonia, hypertonia, dystonia, diplegie, and hemiparesis, among others.

High risk follow up of the preterm and / or LBW infants from 40 weeks up to one year corrected age (VII)

The INFANIB screening or Infant neurological battery test

- This test makes possible to integrate results in relation to the children's neurological evolution, from onset to later findings
- It is specific and sensitive *(Discriminant ability of the Infant Neurological International Battery (**INFANIB**) as a screening tool for the neurological follow-up of high-risk infants in Colombia N Charpak, AM Hoz, J Villegas, F Gil - **Acta Paediatrica**, 2016)*
- Facilitates early detection of neurological disorders
- Offers the possibility of taking timely and adequate therapeutic action to decrease the emergence of inadequate patterns

The necessary elements to conduct the exam are:

- A stretcher with a padded mat, the child must be naked
- The child's corrected age at three, six, nine, and twelve months is used
- The exam must not be performed if the child exhibits irritability, fever, is ill, hungry, sleepy or tired; this could interfere with the results.

Immunization

Vaccines and booster shots	Age	Comments
BCG	Newborn and children over 2000g.	If under 2000g at one month of life, delay until two months of chronological age and administer with the first dose of DPT-Polio.
Polio vaccine	Two, four and six months of chronological age, with booster shots at 18 months, five years and then every 10 years.	Due to the theoretical risk of transmission to other infants, the vaccine should not be given to preterm infants until they are discharged from hospital. Inactivated polio vaccine (IPV) may be used for long term hospitalized infants. It is also recommended if there is group consultation in the KMC.
Hepatitis B	Newborn, two, four and six months of age.	
DPT	Two, four and six months of age, with a tetanus booster shot every ten years.	Diphtheria-tetanus-pertussis Following scientific evidence, it is emphatically recommended to administer it with acellular pertussis component (DPaT), due to the high neurological risk of apnea, hypothermia-induced seizures, and poor tolerance to vaccines.
Haemophilus influenzae type b (Hib)	Two, four and six months of age.	Booster shot at 12 months or at 18 months with pentavalent vaccine.

Immunization (II)

Triple viral vaccine (MMR)	One year chronological age, a booster shot at five years.	Mumps, measles and rubella
Yelllow fever	One year of age, a booster every ten years	
Influenza	Beginning at six months (two doses on the first immunization), booster shots every year.	The seasonal vaccine is administered. It is advised that every family member to be in contact with the child is immunized.
Pneumococcal vaccine	Two, four and six months (booster between one year and 18 months)	
Other optional vaccines		Any additional immunization will depend on the physician's judgment (rotavirus, measles, hepatitis A).

The extended Immunization Program (EPI) depends on each country and needs to be adapted according to local political guidelines.

Remarks

- Health Care Programs with easily defined structure, processes and outcomes as a KMCP are particularly suitable for using simple and effective informatics tools for Quality monitoring-improvement.
- Informatics will not help if there is no clarity about attributes, elements and indicators to be measured

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Monitoring of KMC practice in the KMCP/ 2001-2017/3 COE in KMC

	High risk cohorte		≠ Risks				≠ SE Level	
Cohorte	Global <37weeks or ≤2500g at birth		≤30 Weeks at birth	≤1000g at birth	O2 at Entry in the KMCP		Subsidized health insurance	Private insurance
Total 2001-2017 N° (%)	33.589 (100)		5.526 **(15.5)**	1.130 **(3.4)**	9.310 **(27.7)**		9.197 **(27.4)**	3.300 **(9.8)**

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Characteristics at entry in the KMCP

Cohorte	Global <37weeks or ≤2500g at birth	≤30 Weeks at birth	≤1000g at birth	O2 at Entry in the KMCP	Subsidized health insurance	Private insurance
Neonatal stay (day)	14.9	49	68	26	16.7	17.5
NICU	**55.4%**	**82.4%**	**84.6%**	73%	54.8%	32.9%
Ventilatory support	29,3%	**68,5%**	**72,3%**	25%	26%	39%
O2 at entry in the KMCP	27.7 %	**70.2%**	**78.1 %**	100%	42.5%	7.7%
Weight at entry	**45% ≤2000g**	**2060g** (1150-7790)	**1940g** (850-4150)	**2080g** (850-9802)	**2180g** (1030-7120)	**2250g** (1240-5920)
GA at entry	**66,3% ≤36weeks**	**35 we** (31-52)	**35we** (31,3-51)	**35we** (31-67)	**35.5we** (31,3-65)	**35.2we** (31-54)
PTAGA	61.1% (ATSGA 18.6%)	90.8%	69.0%	76.3%	60.7%	65.7%

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Neurological diagnosis at entry

Cohorte	Global <37weeks or ≤2500g at birth		≤30 Weeks at birth	≤1000g at birth	O2 at Entry in the KMCP		Subsidized health insurance	Private insurance
ICH (%)	8.2		**22.0**	**27.0**	13.1		8.9	8.0
Seizures (%)	0.6		**1.8**	**0.4**	1.1		0.8	0.7
Anoxia at any time during the 5 first mn	26.5		**53.7**	**59.2**	40.3		26.4	23.3

Oftalmological screening

Cohorte	Global <37weeks or ≤2500g at birth		≤30 Weeks at birth	≤1000g at birth	O2 at Entry in the KMCP		Subsidized health insurance	Private insurance
Normal (%)	92.3		69.9	56.1	84.8		87.8	90.5
ROP1 (%)	3.7		15.6	21.7	8.2		6.8	5.1
ROP2 (%)	1.9		7.0	10.1	3.1		4.2	2.9
ROP3 (%)	0.5		2.3	4.9	1.0		0.4	--
ROP2 plus o 3 operated (%)	**1.2**		**5.0**	**6.4**	**2.3**		**0.4**	**1.5**
Blind (%)	0.1		0.1	0.4	0.3		0.4	--
Hypoplasy optical nerve (%)	0.1		--	0.4	0.1		--	--
Catarate (%)	0.1		0.1	--	0.1		--	--
Cong toxoplasmosis (%)	0.1		--	--	0.1		--	--

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Somatic growth during the follow up

Cohorte	Global <37weeks or ≤2500g at birth		≤30 Weeks at birth	≤1000g at birth	O2 at Entry in the KMCP		Subsidized health insurance	Private insurance
Birth weight (g)	2095		1.180	880	1.750		2160	2022
Height at birth (cm)	45.0		38.0	35.0	43		45.0	45.0
HC at birth (cm)	32.0		27.0	25.0	30.5		31.5	31.5
Weight at 40w (g)	2.920		2.950	2.670	2.920		3.110	2.930
Height at 40w (cm)	47.2		47.0	45.0	47.0		47.6	47.5
HC at 40w (cm)	34.6		34.6	33.8	34.8		34.5	35.0
Weight at 3 m (g)	5.600		5.330	4.830	5.530		5.690	5.570
Height at 3m (cm)	58.0		57.0	55.2	57.5		58.1	58.0
HC at 3m (cm)	40.0		39.8	38.9	40.0		39.7	40.2
Weight at 1 year (g)	**8.610**		**8.330**	**7.735**	**8.610**		**8.630**	**8.640**
Height at 1 year (cm)	**72.0**		**72.0**	**70.0**	**72.0**		**72.5**	**72.0**
HC at 1 year (cm)	**45.5**		**45.0**	**44.5**	**46.2**		**45.0**	**46.0**

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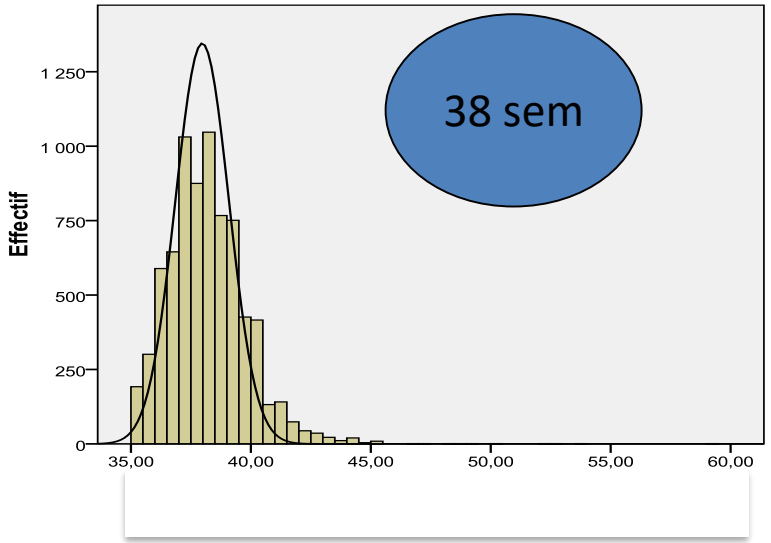
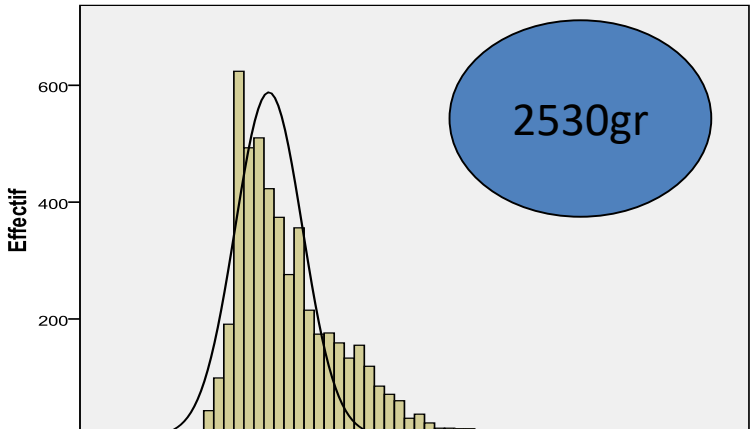
When the child is not tolerating the Kangaroo position?

EDAD GESTACIONAL A LA SALIDA DE LA PC

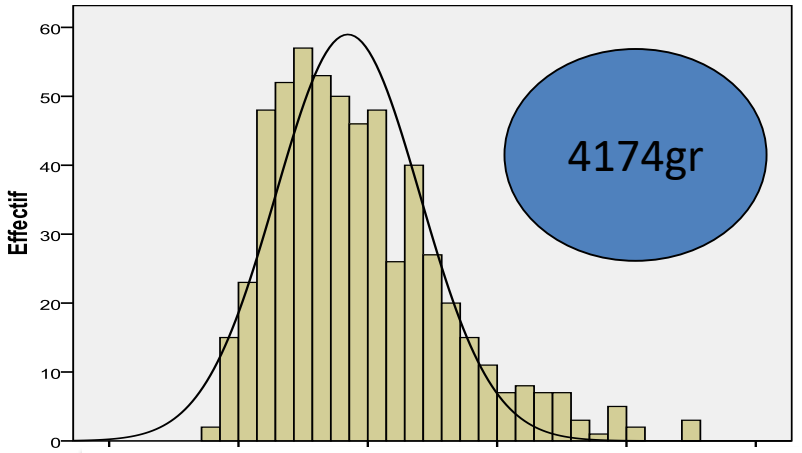


PESO DE SALIDA DE LA PC



Weaning of oxygen during the follow up?

PESO DE DESTETE DEL OXIGENO



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Neurological screening

Cohorte	Global <37weeks or ≤2500g at birth		≤30 Weeks at birth	≤1000g at birth	O2 at Entry in the KMCP		Subsidized health insurance	Private insurance
40 weeks (%) Hypotonic Hypertonic	10.1 1.7		14.5 2.9	15.7 3.4	12.1 2.4		10.6 1.7	10.1 2.2
3 months Transitory **(%)** Abnormal	36.9 1.2		45.2 1.6	57.8 4.1	41.1 1.7		37.9 1.1	35.5 1.3
6 months Transitory **(%)** Abnormal	**38.6** **2.0**		**46.9** **4.4**	**50.4** **9.4**	**41.6** **3.2**		37.2 1.2	34.4 1.6
9 months Transitory **(%)** Abnormal	**13.6** **1.9**		**22.3** **5.3**	**27.8** **7.4**	**16.6** **3.5**		18.1 0.7	9.6 1.9
12 months Transitory **(%)** Abnormal	5.1 1.6		13.1 3.7	17.2 6.1	7.8 2.8		7.1 0.8	4.3 2.1
Risk of Cerebral Palsy (%)	**1.5**		**5.3**	**6.1**	**2.9**		**2.4**	**2.1**

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Screening of the psychomotor developement (Griffith + Bailey)

Cohorte	Global <37weeks or ≤2500g at birth		≤30 Weeks at birth	≤1000g at birth	O2 at Entry in the KMCP		Subsidized health insurance	Private insurance
PMD 6 months (%) Light	10.1		13.4	**18.9**	12.6		13.7	9.7
Moderate	1.2		3.1	**5.5**	2.0		0.7	--
Severe	0.6		1.3	**3.1**	1.5		--	3.2
PMD12 months (%) Light	4.9		15.6	**18.3**	9.5		19.5	4.3
Moderate	1.1		2.3	**4.8**	1.7		2.9	0.8
Severe	0.5		0.5	**1.2**	0.7		1.2	1.5
IQ (P) **6 months**	93		91	**88**	92		92	92
IQ (P)**12 months**	92		90	**89**	93		**86**	94

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Neurosensorial screening

Cohorte	Global <37weeks or ≤2500g at birth		≤30 Weeks at birth	≤1000g at birth	O2 at Entry in the KMCP		Subsidized health insurance	Private insurance
Audiometry (%)								
Disminution of audition	2.2		2.9	4.2	2.8		3.2	1.7
Deafness	0.1		0.3	0.8	0.1		--	--
Optometry (%)								
Miopia	**1.9**		**4.1**	**5.7**	**2.8**		**1.9**	**1.7**
Astigmatisme	**26.0**		**23.2**	**25.2**	**24.2**		**13.9**	**27.1**
Hypermetropy	**29.5**		**27.0**	**25.2**	**30.8**		**12.0**	**30.5**
Other	**2.4**		**2.8**	**2.4**	**2.4**		**1.9**	**1.7**

Feeding patterns up to 3 months of corrected age

Cohorte	Global <37weeks or ≤2500g at birth		≤30 Weeks at birth	≤1000g at birth	O2 at Entry in the KMCP		Subsidized health insurance	Private insurance
Exclusive BF at 40 w %	**68,5**		**51,7**	**39,5**	**46,4**		**58,9**	**63,2**
Exclusive BF up to 3 months of CA %	**35**		**18,1**	**15,4**	**31,2**		**37,4**	**24,5**
BF ± formula up to 3 months of CA %	**79,2**		**78,5**	**73,1**	**71,3**		**76,1**	**70,4**

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Lost to follow up and mortality during the follow up

Cohorte	Global <37weeks or ≤2500g at birth		≤30 Weeks at birth	≤1000g at birth	O2 at Entry in the KMCP		Subsidized health insurance	Private insurance
Follow up completed or in course (%)	85.0		83.9	86.9	86.5		72.5	81.1
Lost to follow up during the year (%)	**13.5**		13.3	8.6	11.4		23.7	18.2
Death during the year (%)	**0.9**		**1.8**	**2.7**	**1.4**		**1.1**	**0.4**

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Acumulated mortality during the follow up

Cohorte	Global <37weeks or ≤2500g at birth		≤30 Weeks at birth	≤1000g at birth	O2 at Entry in the KMCP		Subsidized health insurance	Private insurance
Readmittion (%) at least once during the year	**20.1**		32.0	35.6	22.1		30.1	12.2
Cumulated stay (%) for readmittion during the year	**3.5**		6.0	6.8	3.3		5.9	0.9
Diagnosis of pulmonary pathology when readmitted (%)	**27.3**		28.4	33.3	24.6		34.9	22.1

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Vaccination at the end of the follow up

Cohorte	Global <37weeks or ≤2500g at birth
BCG (%)	**99,8**
DP(acelular**) T Polio** (dead virus) **Hemofilus y Hep B (%)**	**99,6**
Neumo y rotavirus (%)	**98**
MMR (%)	**98**

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Conclusion

- The original KMC method, including all the components, creates an interaction between health, environment and development through a driven force that influence, at the right moment (impact time window) the brain maturation ex utero and the capacity building of parents of the premature and low birth weight infants who become progressively more aware of the child and more prone to sensitive and nurtured care during the first year of life of their infant.
- The KMCP is often the unique opportunity to follow the fragile infants in a high risk outpatient clinic, it is cost effective and our experience, based in data recollected for more than 25 years, demonstrates that it is feasible in a middle or low income country.

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Thank you

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