

Neonatal mortality remains unacceptably high No stone should remain unturned



RareX CONFERENCE 2018

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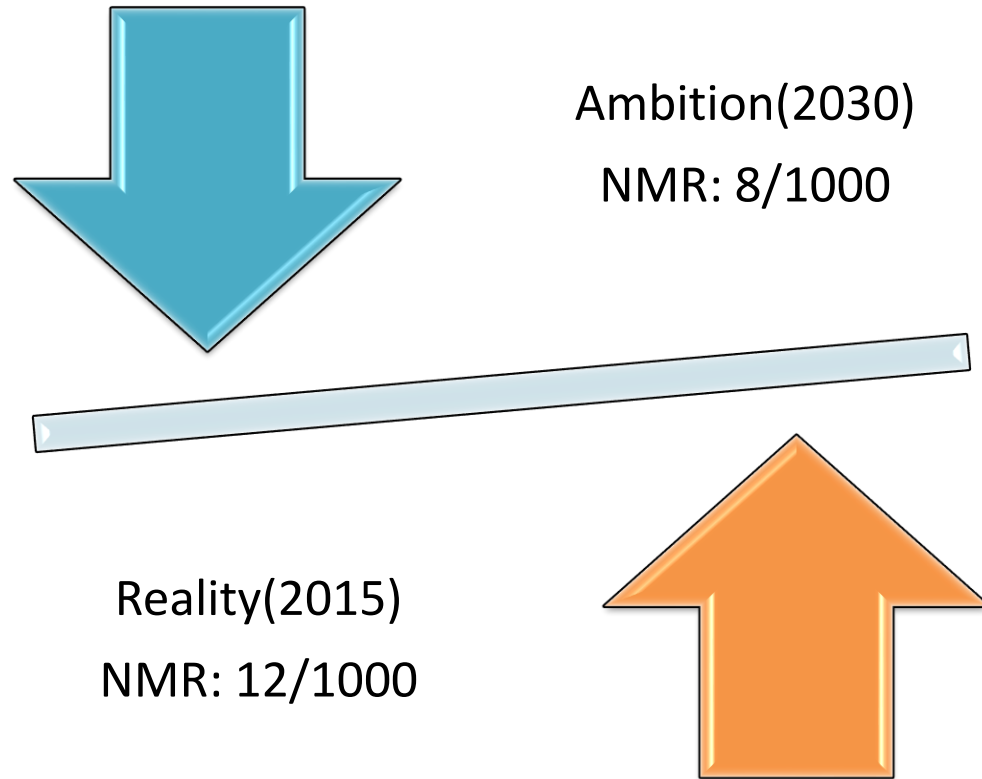
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INTRODUCTION



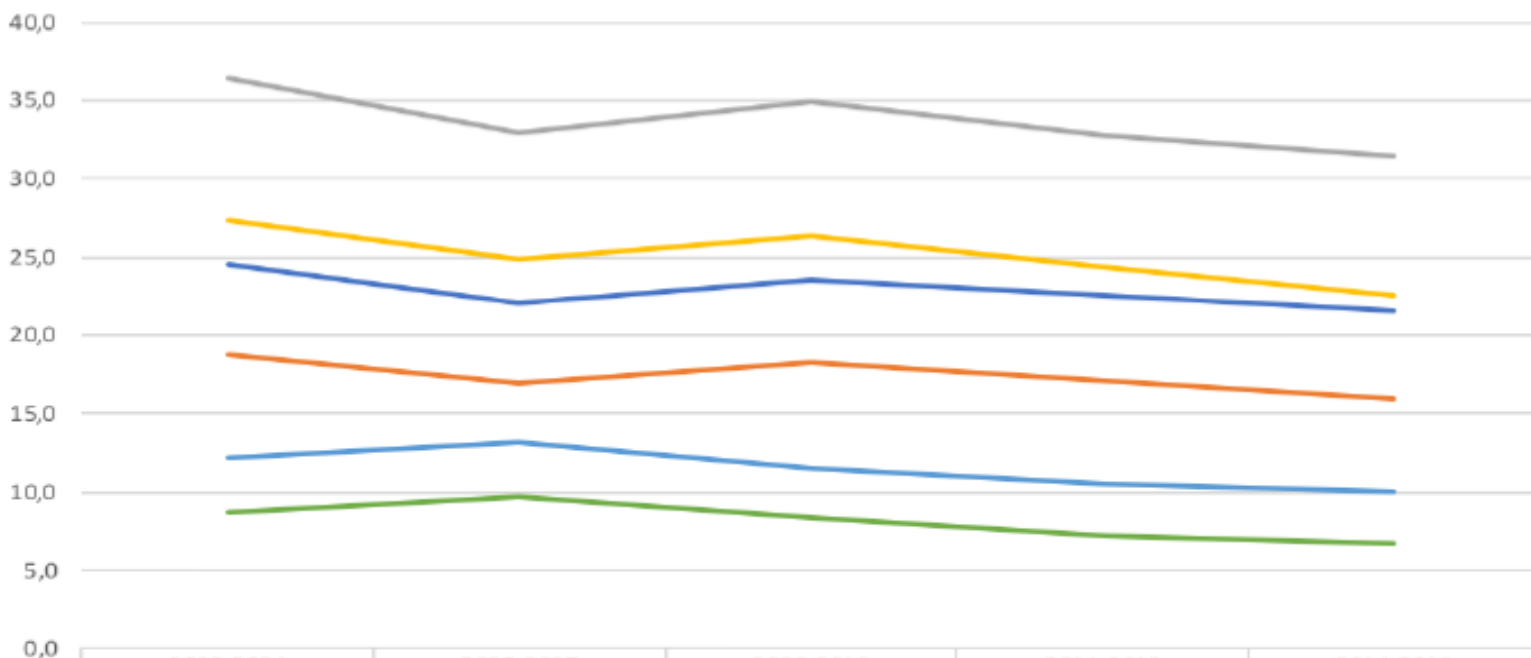
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SAVING BABIES REPORT (2014-2016)



Comparison of PPIP rates 2002-2016, South Africa



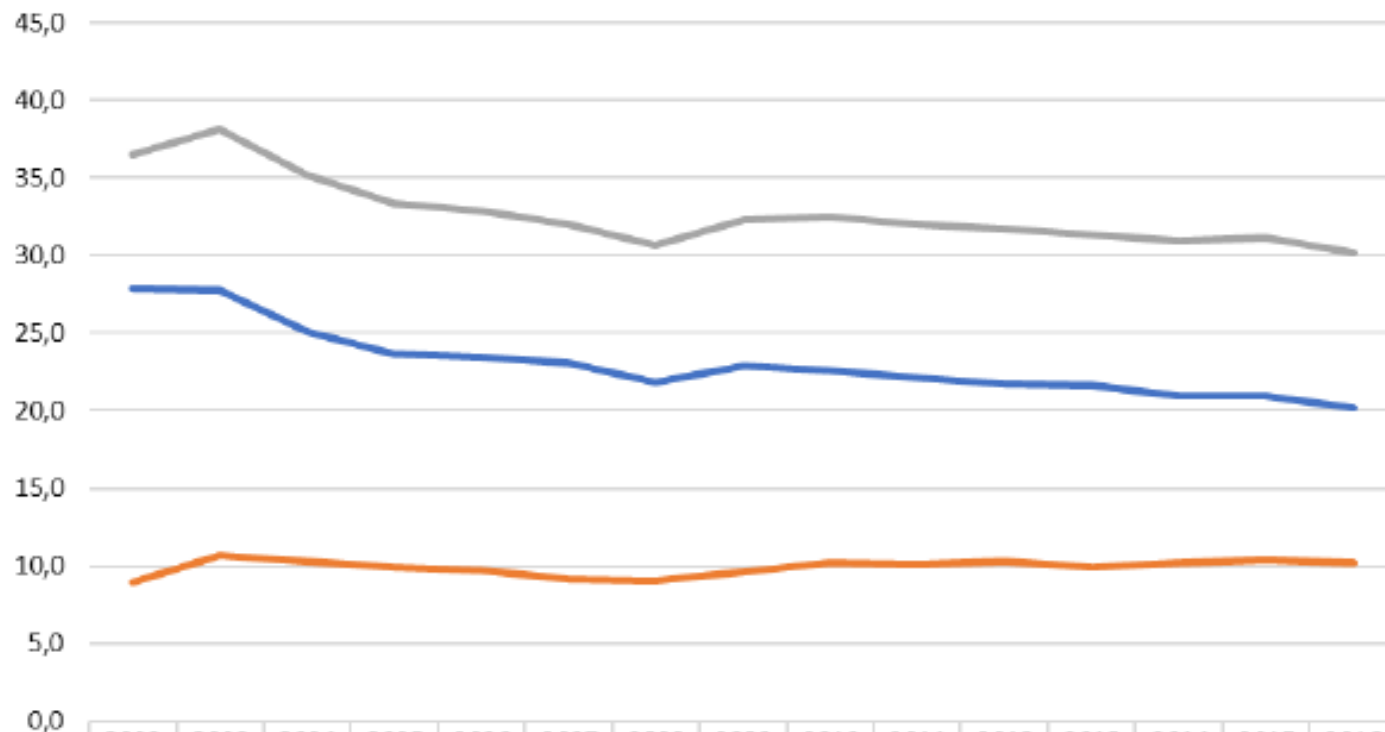
	2002-2004	2005-2007	2008-2010	2011-2013	2014-2016
Stillbirth Rate 500g+	24,5	22,1	23,6	22,5	21,6
Stillbirth Rate 1000g+	18,7	17,0	18,2	17,2	15,9
PNM Rate 500g+	36,4	33	34,9	32,8	31,4
PNM Rate 1000g+	27,3	24,8	26,4	24,4	22,6
Early Neonatal MR 500g+	12,2	13,1	11,5	10,6	10,1
Early Neonatal MR 1000g+	8,7	9,7	8,4	7,3	6,7



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SAVING BABIES REPORT (2014-2016)



	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012	2013	2014	2015	2016
Stillbirth rate	27,9	27,8	25,1	23,6	23,5	23,1	21,8	22,9	22,6	22,1	21,7	21,6	20,9	21,0	20,2
Early neonatal mortality rate	8,9	10,7	10,3	10,0	9,7	9,1	9,0	9,6	10,2	10,1	10,3	9,9	10,2	10,4	10,2
Perinatal mortality rate	36,5	38,2	35,1	33,3	32,9	32,0	30,7	32,3	32,5	32,0	31,7	31,3	30,9	31,1	30,2



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Focus: Unexplained inter uterine deaths especially in the third trimester and without obstetrical high risk factor

48%



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PRIMARY CAUSE OF DEATH ALL BABIES: >500G



Description	Number	% of total
Spontaneous preterm labour	15 912	22.9
Unexplained intrauterine death	15 798	22.8
Hypertensive disorders	10 317	14.9
Intrapartum asphyxia	9 316	13.4
Antepartum haemorrhage	7 357	10.6
Foetal abnormality	3 336	4.8
Infections (excluding maternal HIV disease)	2 035	2.9
Intrauterine growth restriction (IUGR)	1 600	2.3
No obstetric cause	1 473	2.1
Maternal disease	1 115	1.6
Miscellaneous	889	1.3
Trauma	272	0.4



NEONATAL CAUSE OF DEATH > 1000G



Description	Number	% of total
Hypoxia	5 939	34.9
Immaturity related	4 984	29.3
Infection	2 279	13.4
Congenital abnormalities	2 151	12.6
Miscellaneous	1 188	7
Unknown cause of death	411	2.4
Trauma	73	0.4



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Patients associated avoidable factors



PATIENT ASSOCIATED	Number	% of group
Inappropriate response to poor foetal movements	12 871	25.9
Never initiated antenatal care	8 638	17.4
Booked late in pregnancy	8 506	17.1
Delay in seeking medical attention during labour	8 101	16.3
Infrequent visits to antenatal clinic	1 829	3.7
Other patient associated factors	1 804	3.6
Failed to return on the prescribed date	1 792	3.6
Inappropriate response to antepartum haemorrhage	1 550	3.1
Smoking	999	2
Inappropriate response to rupture of membranes	826	1.7
Alcohol abuse	619	1.2
Declines admission/treatment for personal/social reasons	589	1.2
Attempted termination of pregnancy	493	1
Delay in seeking help when baby ill	441	0.9
Illegal drug use	287	0.6
Assault	89	0.2
Partner/family declines admission/treatment	54	0.1
Infanticide	31	0.1



Administration associated avoidable factors



No syphilis screening performed at hospital / clinic	309	2.9
Congenital abnormality not diagnosed: No ultrasound service available	308	2.9
Result of syphilis screening not returned to hospital/clinic	242	2.3
Theatre delay: All theatres occupied	225	2.1
Inadequate theatre facilities	207	1.9
No dedicated high risk clinic at referral hospital	204	1.9



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HCW Associated factors



Inadequate / No advice given to mother	841	3.2
Physical examination of patient at clinic incomplete	800	3
Neonatal care: management plan inadequate	795	3
Foetal distress not detected intrapartum; foetus not monitored	776	2.9
No response to poor uterine fungal growth	723	2.7
Medical personnel underestimated foetal size	720	2.7
No response to history of stillbirths, abruption etc.	697	2.6
Neonatal care: inadequate monitoring	694	2.6



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Proposed solutions(know the numbers)



Type of indicator	Core ENAP indicators (source)	Additional indicators (source)	Not available yet, no data source	Proposed: Neonatal Register Proposed: DHIS Captured in DHIS;
Impact (3)	1. Maternal mortality ratio, replaced by early NNDR (DHIS)*			ENND per weight banding
	2. Stillbirth rate (DHIS)	Intrapartum Stillbirth Rate (PPIP: FSB 2,5kg)*		SB rate per weight banding
	3. Neonatal mortality rate (DHIS)	Low birth weight rate (DHIS)		LBWR per weight banding
			Preterm birth rate	Preterm birth rate
			Small for gestational age	Small for gestational age rate
		Neonatal morbidity rates* ,i.e. disease specific rates egg infection (PPIP)		Disease specific rates according to ICD 10 coding Age specific: seven to seven days; eight to 28 days 29 days -11 months
			Rates of long term disability after neonatal conditions	Resuscitation: CPAP, Ventilation



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Data collection (primary source- Admission)



NEONATAL REGISTER: MONTH: _____

Admission															Admission from			Birth Weight Category			Reason for Admission			HIV Exposure
Date (e.g., 1 July 2017)	Carry over midnight	Name of baby:	File number	Admission Number	Mother's name	Mother's File number	Date of Birth dd/mm/yy	Place of Birth	Admission born in facility (specify labour/theatre/postnatal)	Admission from home	Transfer in from other hospital or MOU (specify hospital/MOU)	Transfer in from other ward (specify ward within hospital)	Birth Weight in gram	<1000gram	1000 - 1499gram	1500 - 1999gram	2000 - 2499 gram	≥2500 gram	Admission weight in g	Temperature on Admission	ANC Steroids (Y=yes, N=No, NA=Not applicable)	(RDS, NNJ, Prem, Infection, Neonatal encephalopathy, Asphyxia, Cong Abn, other)	HIV	Total Admissions
Totals																								
1																								
2																								
3																								
4																								

Neonatal deaths in children's ward



Period	First triennial period (2008-2010) Audited NND=1221			Second triennial period (2011-2013) Audited NND=1532			Third triennial period (2011-2013) Audited NND=1404		
	Number	Percent	Child	Number	Percent	Child	Number	Percent	Child
Length of stay									
Death within 24 hours	595	49%	34%	695	45%	34%	548	39%	32%
Nutrition									
Severe acute malnutrition	80	7%	36%	81	5%	33%	79	6%	33%
Unknown	88	7%	7%	95	6%	6%	97	7%	6%
HIV									
Exposed	427	35%	24%	602	39%	23%	518	36%	19%
Infected	40	3%	28%	38	2%	21%	28	2%	17%
Unknown	553	45%	34%	510	33%	28%	360	26%	23%
PMTCT									
Mother negative at delivery	279	23%	20%	480	31%	31%	535	38%	37%
Unknown	399	33%	49%	397	26%	38%	282	20%	31%
Burden of disease									
Septicaemia	325	33%	23%	380	32%	24%	408	29%	17%
Was death avoidable?									
Yes	308	25%	30%	318	21%	34%	380	27%	32%
Not Sure	514	42%	41%	717	47%	38%	575	41%	34%
Total (Yes and unsure)	822	67%	71%	1035	68%	72%	955	68%	66%

Strategic objectives for intervention



- ❑ to develop and implement the genetic services guidelines
- ❑ to develop and strengthen national birth defects surveillance and evaluation mechanisms;
- ❑ to integrate birth defects prevention strategies into public health, nutrition and other relevant programmes, as appropriate;
- ❑ Develop a long-term (chronic) disease model of care and support for cases and families across all levels of care;
- ❑ Increased community education, engagement and participation in service demand, access and utilization; and
- ❑ to develop and expand national, regional and international multi-sectoral partnerships and networks to support birth defects prevention and control programmes



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