

FROM COMMON TO RARE

Neil McKerrow

Rare Diseases Conference

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WHERE ARE WE GOING - GLOBAL?



Developed in collaboration with **TROLLBÄCK + COMPANY** | TheGlobalGoals@trollback.com | +1.212.529.1010
For queries on usage, contact: dpicampaigns@un.org

SURVIVE, THRIVE, TRANSFORM

WHERE ARE WE GOING – LOCAL?

- NSDA

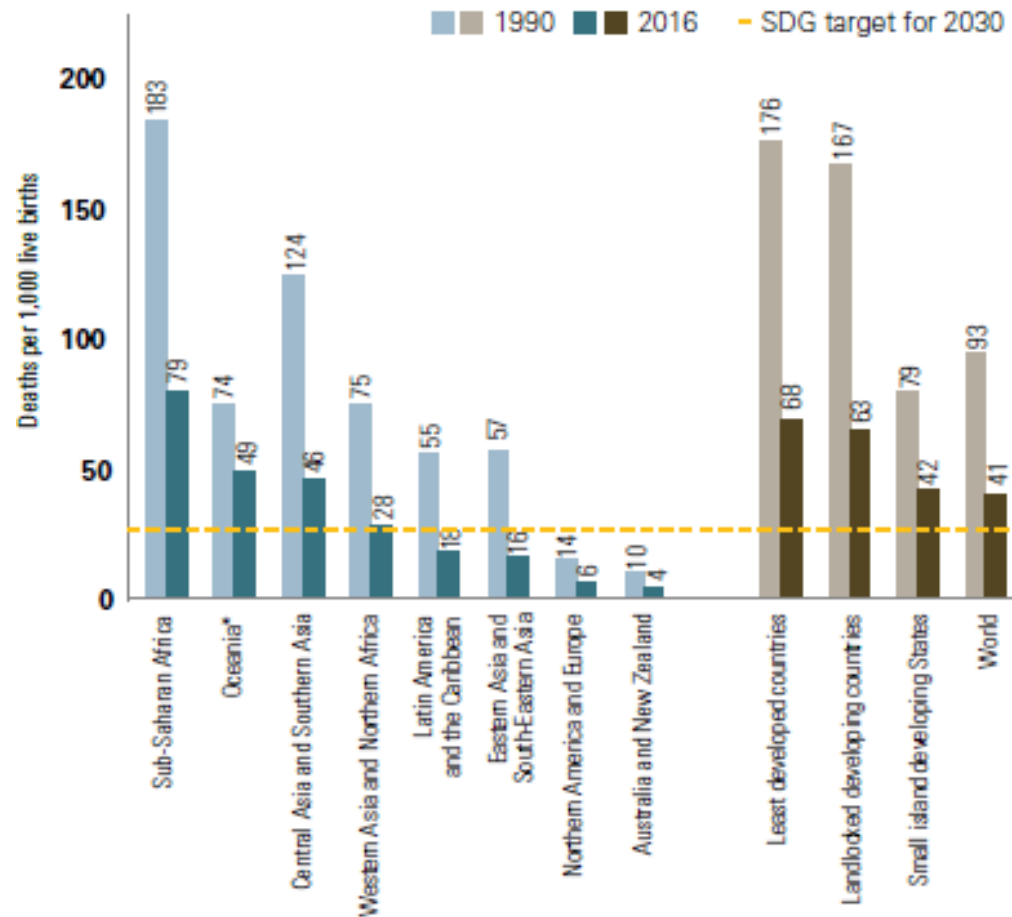
- Outcome 2: a long and healthy life for all South Africans

- Output 1: Increasing life expectancy
- Output 2: Decreasing maternal and child mortality rates
- Output 3: Combating HIV and AIDS and decreasing the burden of disease from TB
- Output 4: Strengthening health system effectiveness

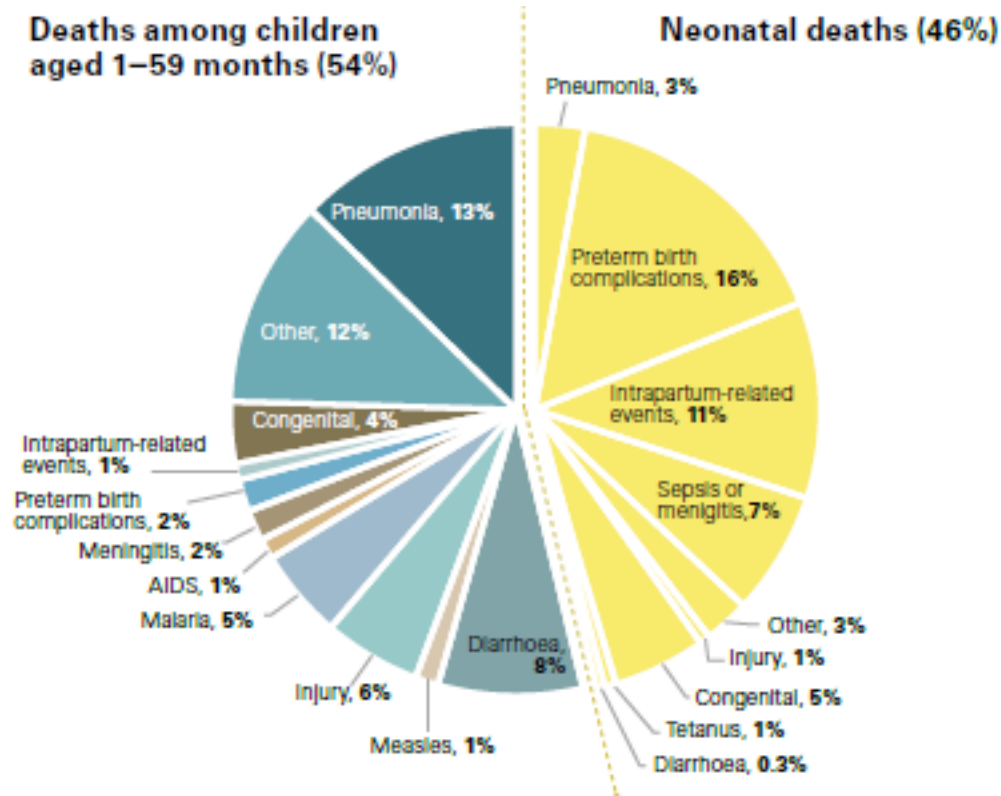
FOCUS ON SURVIVE

WHERE ARE WE – GLOBAL?

U5MR by SDG region

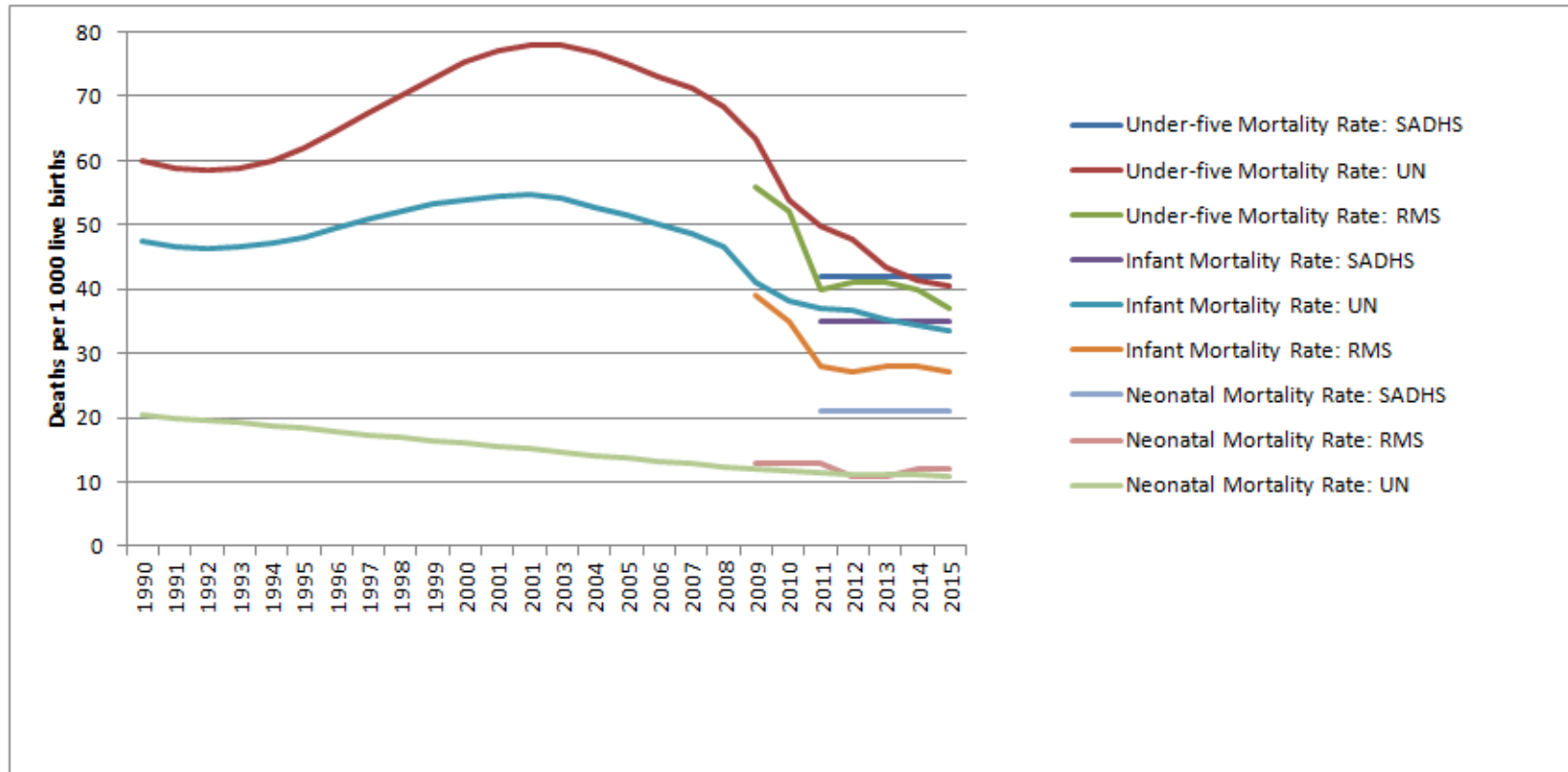


CAUSE OF U5 DEATH, GLOBAL: 2017



Nearly half of all deaths in children under age 5 are attributable to undernutrition

TREND IN U5MR: RSA

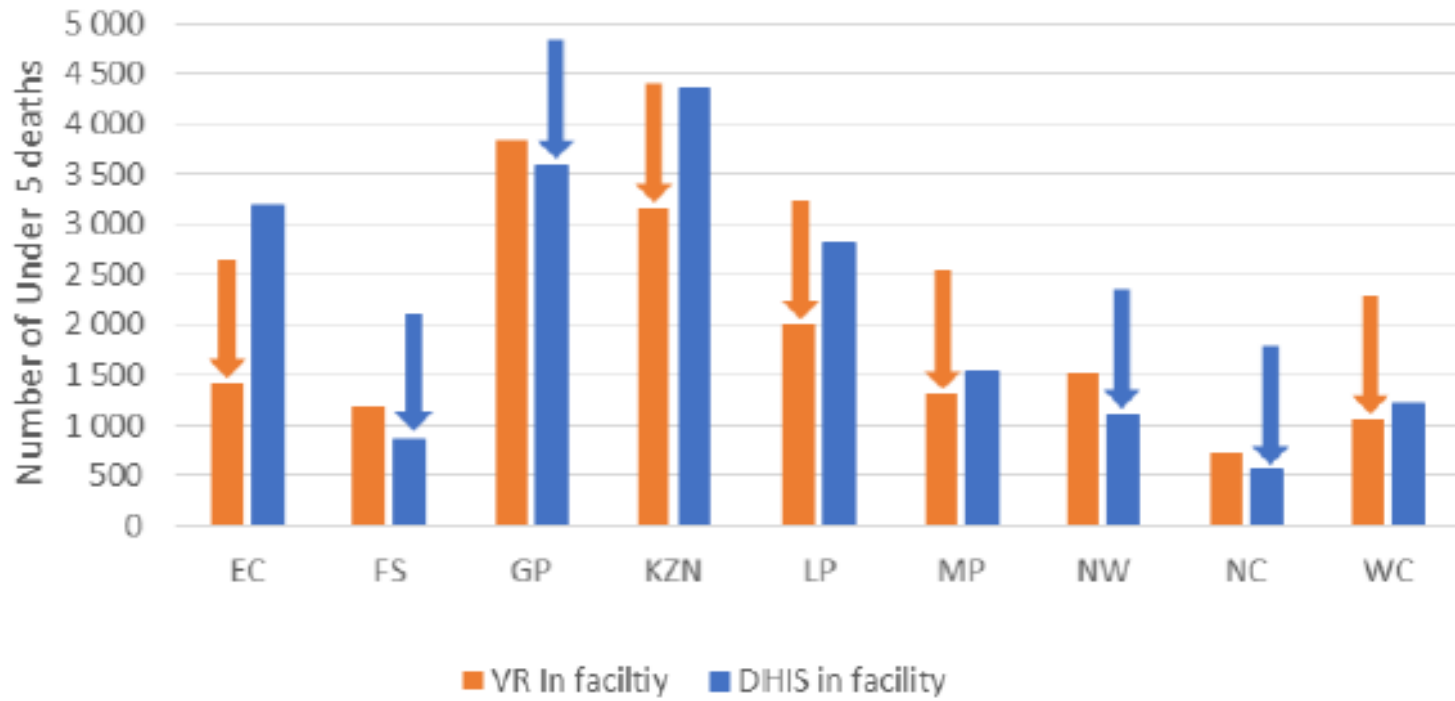


MISSING DEATHS

	VR 2011	CENSUS 2011	CENSUS/VR		VR 2015	CS 2015	CS/VR
EC	3 687	7 759	2.10		3 240	4 760	1.47
FS	3 754	4 015	1.07		2 356	2 361	1.00
GP	8 330	8 591	1.03		7 348	7 909	1.08
KZN	7 194	14 842	2.06		5 372	8 568	1.60
LP	4 204	5 405	1.26		4 426	5 329	1.20
MP	2 976	5 223	1.75		2 597	3 776	1.45
NW	3 830	4 774	1.25		3 171	4 559	1.44
NC	1 222	1 239	1.01		1 068	1 059	0.99
WC	2 462	1 713	0.70		2 319	1 859	0.80
RSA	37 908	54 250	1.43		31 938	40 180	1.26

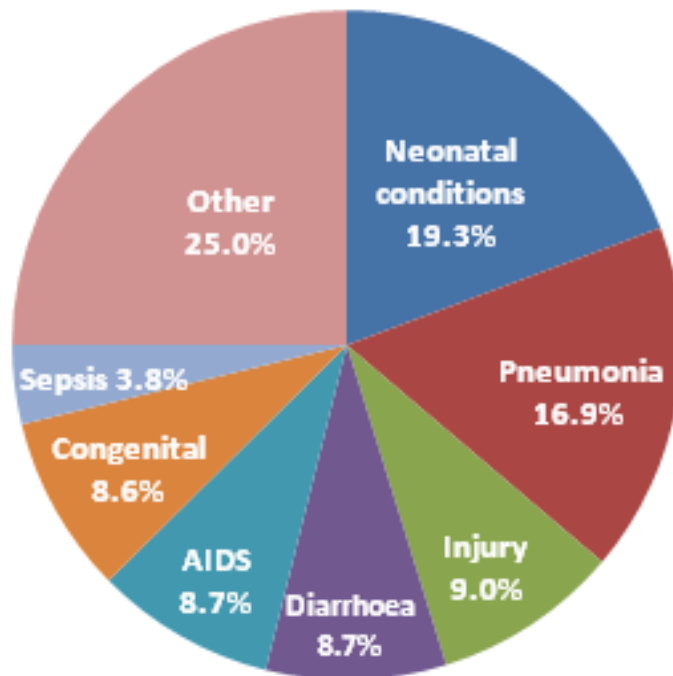
Source: StatsSA - VR 2011; Census 2011; StatsSA - VR 2015 & CS 2015.

UNDER REPORTING

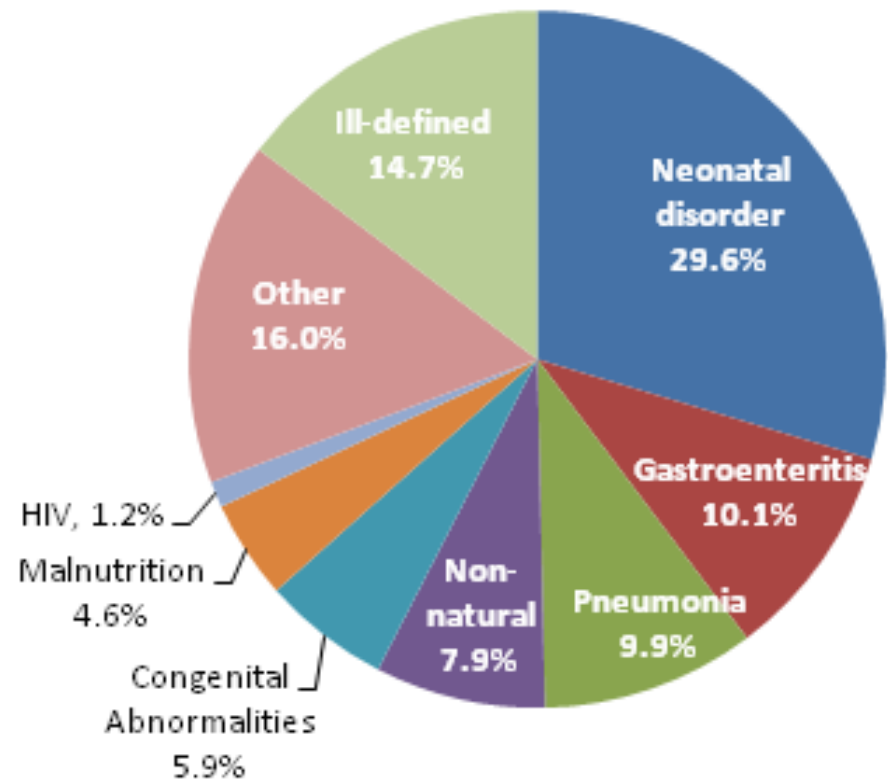


CAUSE OF U5 DEATH, RSA: 2015

UN IGME



STATS SA VR



CAUSE OF U5 HOSPITAL DEATHS

CHILD PIP 2005 – 2017

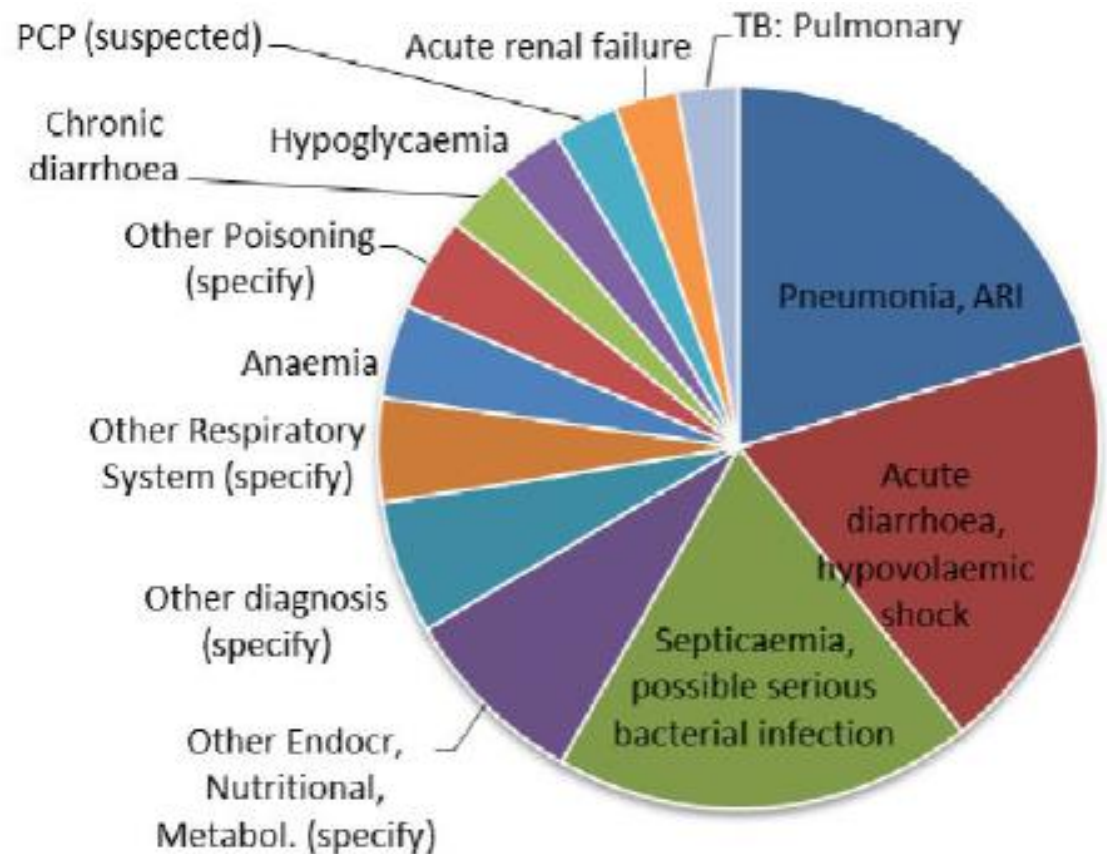
60 575 deaths

3.2% Congenital Disorder

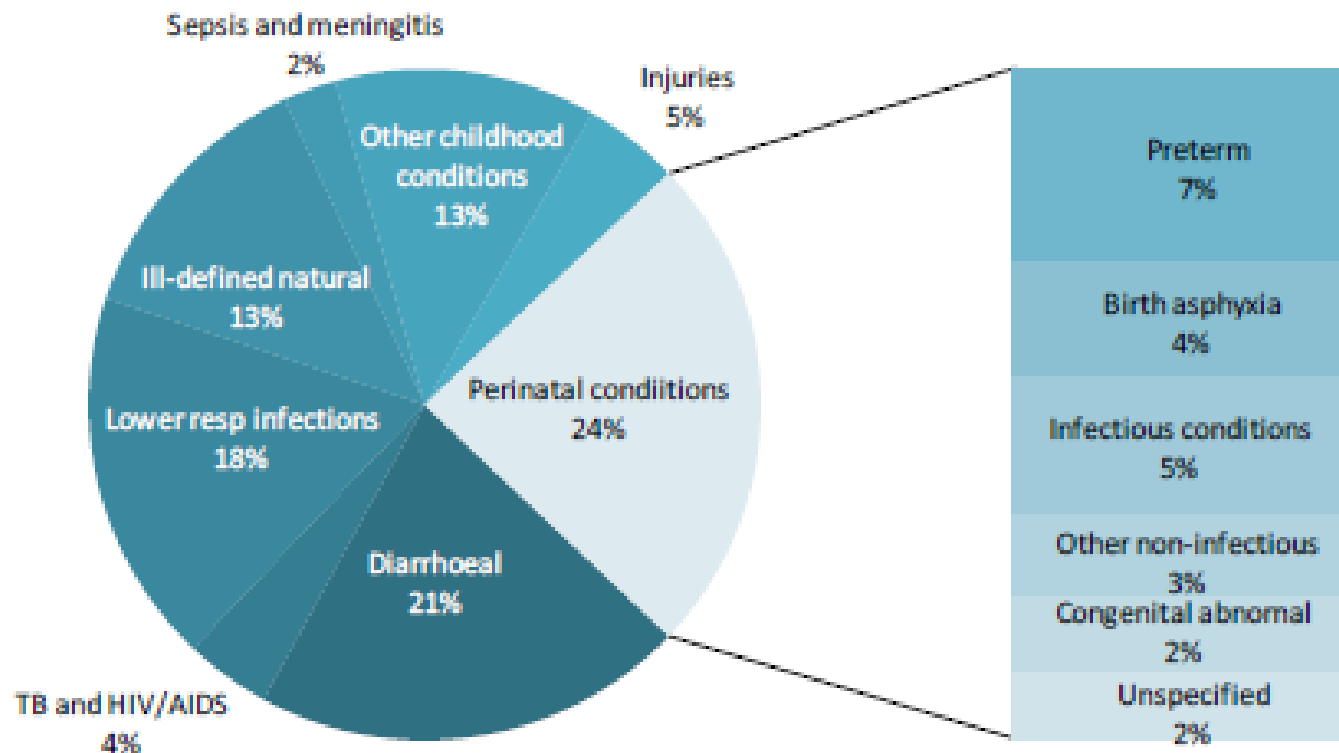
0.4% 1° CoD

2.8% underlying cause

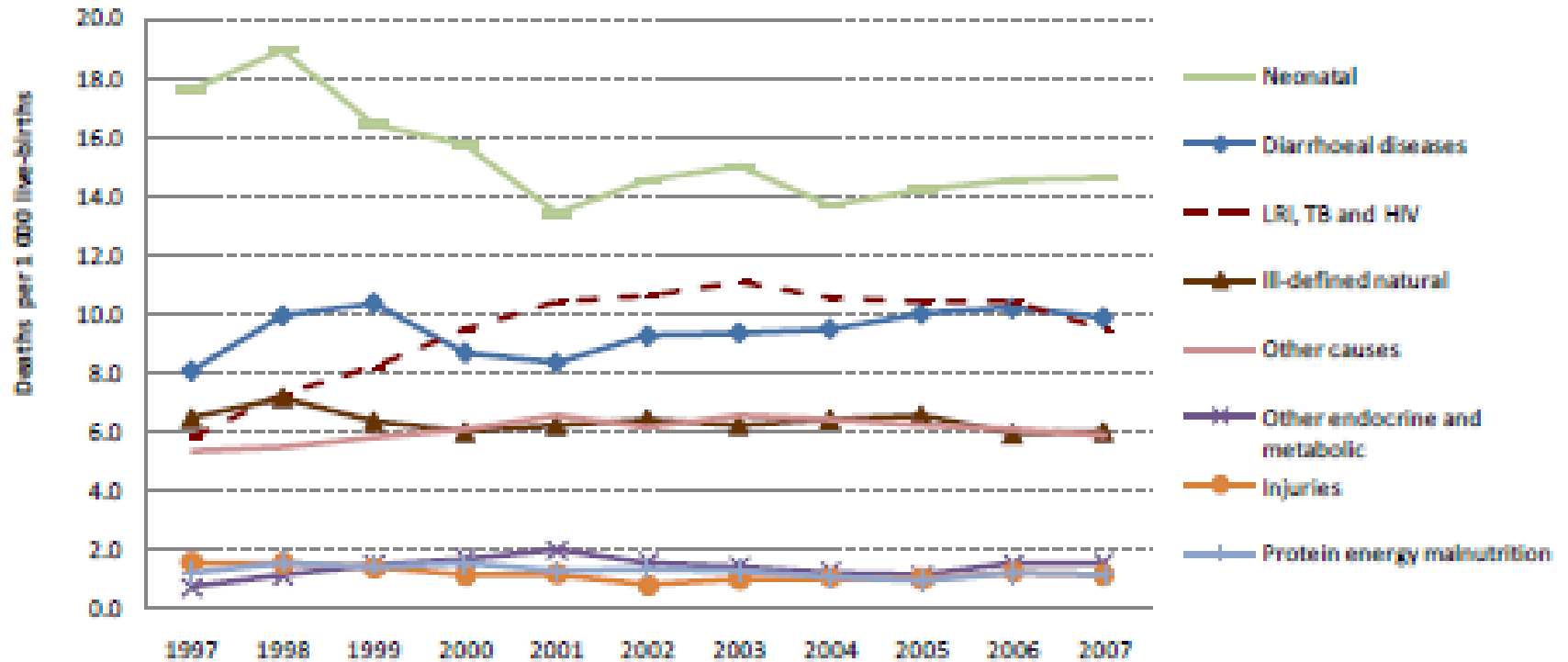
Patrick et al SAMJ . 2018



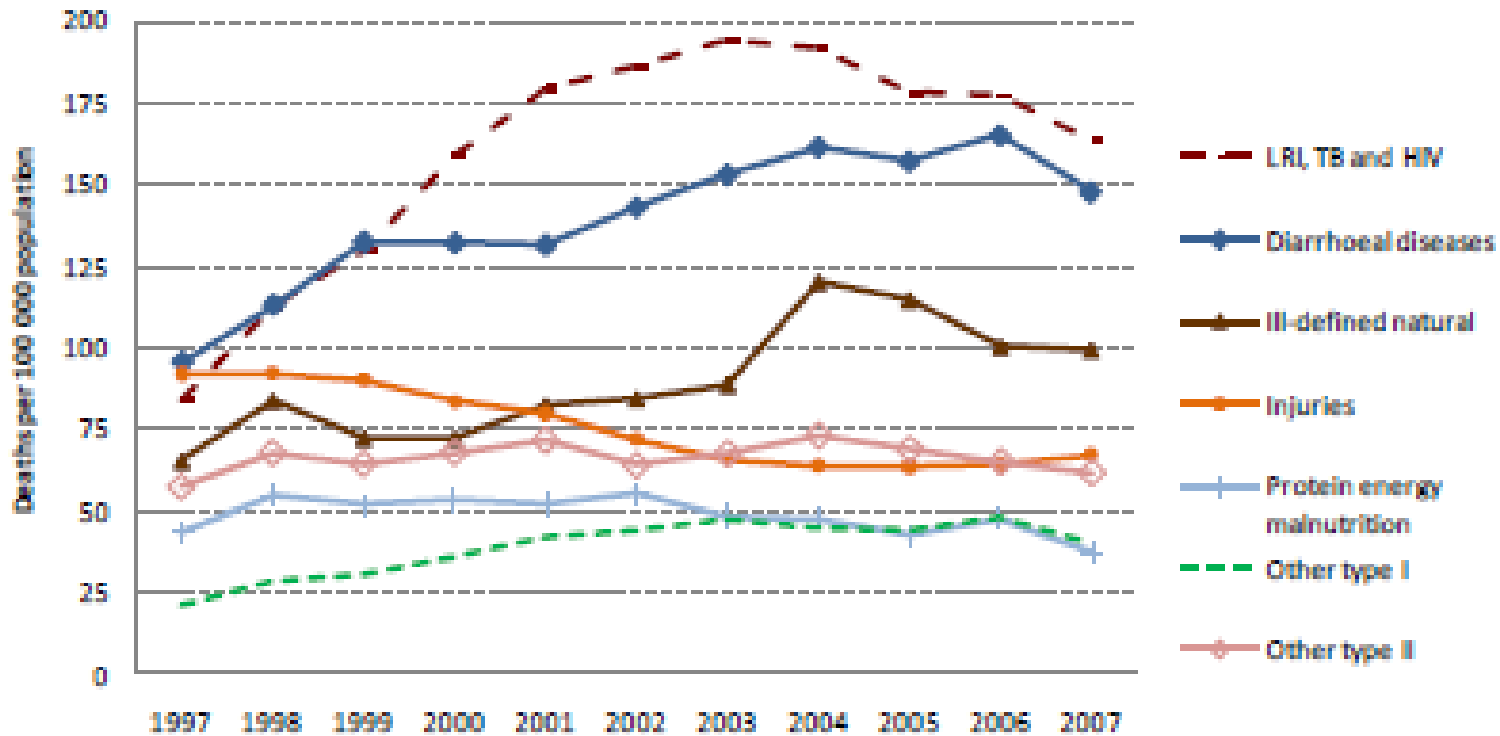
CAUSE OF U5 DEATH, RSA 2007



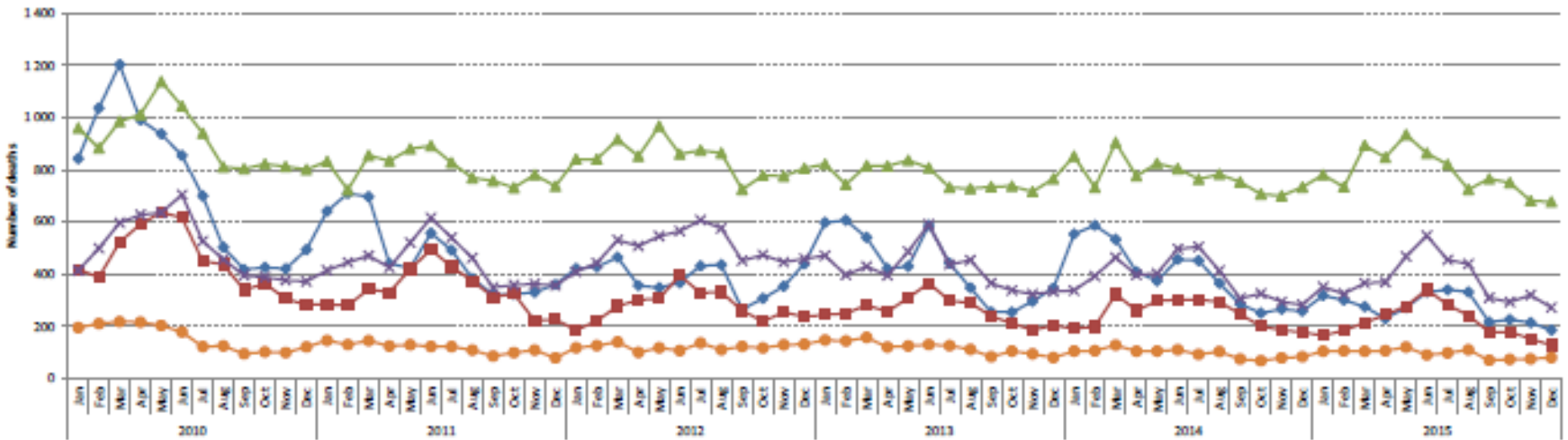
CAUSE OF INFANT DEATHS: RSA



CAUSE OF DEATH 1 – 4 YRS: RSA



TREND IN CAUSE OF U5 DEATHS: RSA



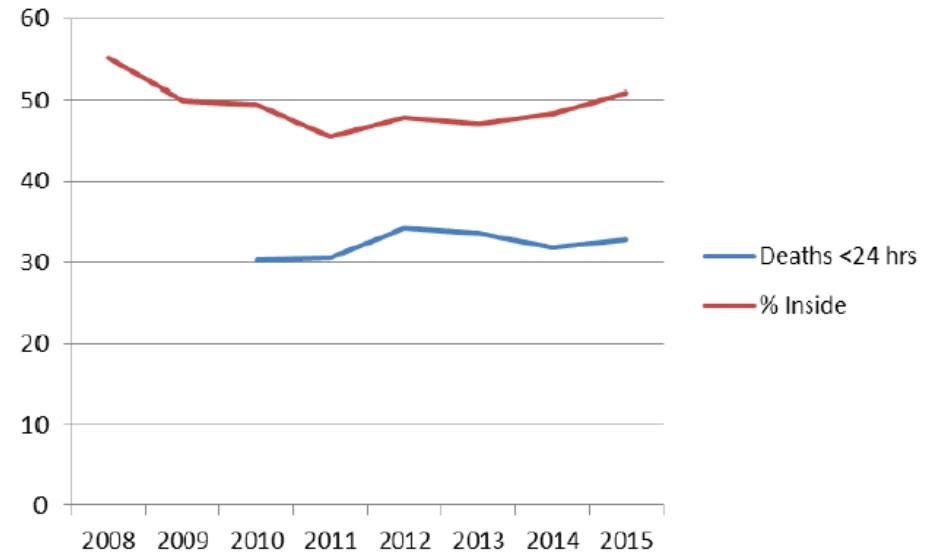
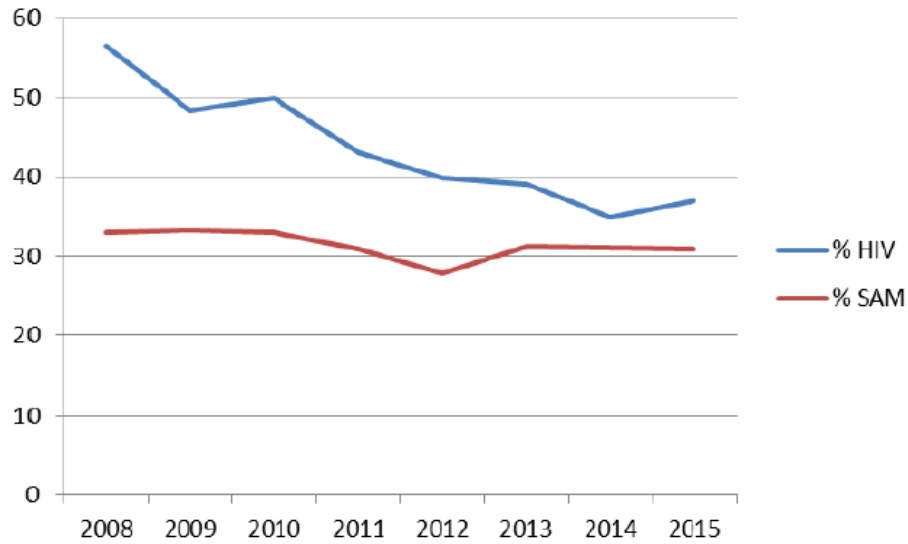
- Neonatal
- Gastrointestinal infection
- No cause
- Pneumonia
- HIV

TREND IN U5 CAUSE OF DEATH

Cause	2011	2012	2013	2014	2015
Neonatal disorder	23.1	25.0	22.6	23.4	29.6
Gastroenteritis	15.0	12.3	14.6	14.0	10.1
Pneumonia	11.0	11.2	11.2	10.8	9.9
Non-natural	6.3	7.1	7.0	7.3	7.9
Malnutrition	3.9	3.9	3.7	4.7	4.6
Congenital Abnormality	3.9	-	4.2	4.9	5.9
Tuberculosis	2.0	1.6	1.5	1.4	1.1
HIV	1.2	1.0	1.7	1.4	1.2
Other	19.1	-	18.6	17.9	14.9
Ill defined	14.5	-	14.9	14.2	14.7

Source: StatsSA VR database 2011 – 2015

TREND IN CONTRIBUTING FACTORS: RSA



ANTICIPATED CONGENITAL DISORDERS

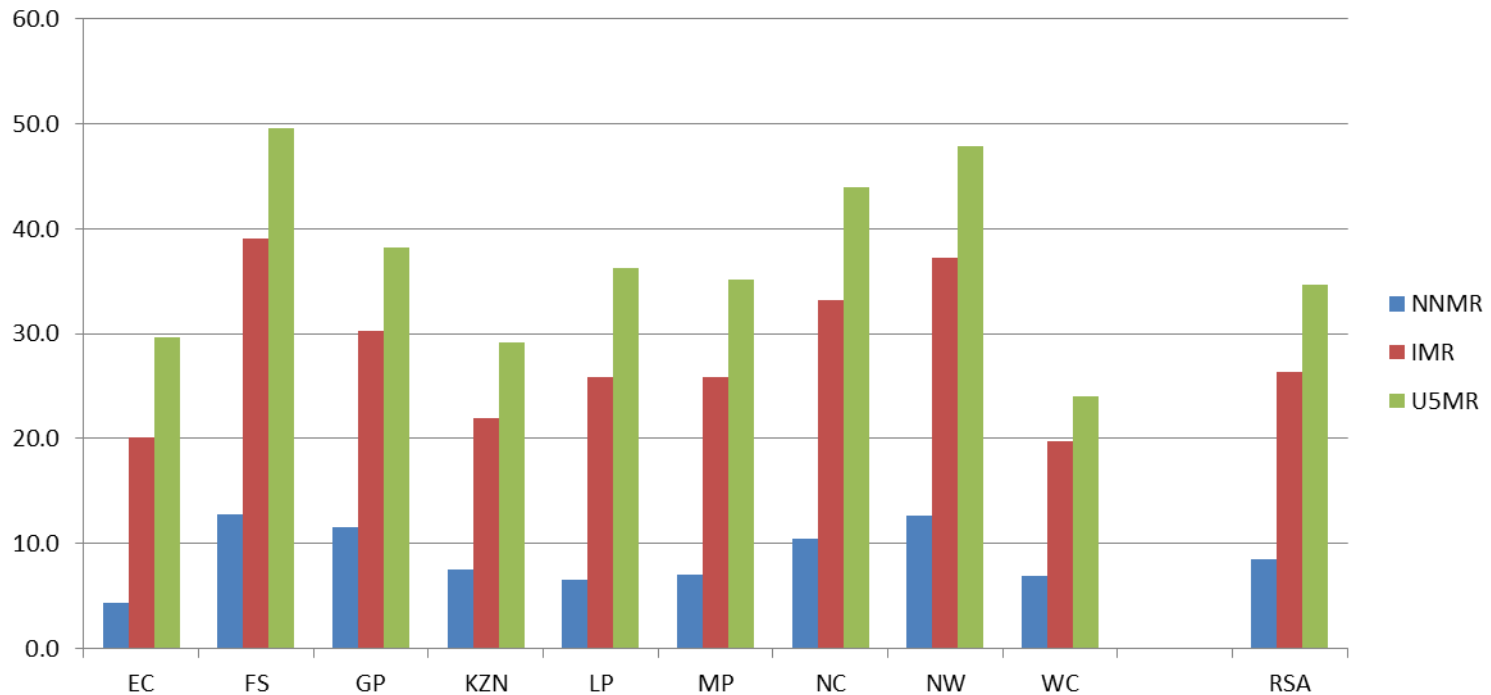
		Birth prevalence	N° / year
Single gene disorders			
	Dominant single gene disorders	7/1000	7,735
	Recessive single gene	1,7/1000	1,879
	X linked single gene disorders	1,3/1000	1,437
			11,051
Chromosomal disorders		4,4/1000	
	Down syndrome		2,321
	Sex chromosome		1,989
	Other chromosome		553
			4,863
Malformations and birth defects of multifactorial origin			
	Cardiovascular system		8,730
	Genitalia		8,288
	Musculo-skeletal System		9,614
	Digestive System		3,094
	Neural Tube defects		2,542
	Other CNS		1,437
	Urinary tract		1,768
	Facial clefts		1,547
	Ear, face, neck		553
	Eye		332
	Respiratory system		332
	Other and multiple birth defects		2,984
	Haemolysis causing NNJ		507
Unknown cause			1,326
	Foetal alcohol		14,000
Total		60,1000	57,054
			72,968

LONG TERM HEALTH CONDITIONS

Condition/Disease	Prevalence / Annual incidence	N° of new cases per year	N° in care
Asthma	10% - 15%		
HIV	1.5% of children will require HAART	15 000	100 000
Rheumatic heart disease	1 – 7 / 1 000 children 5 – 15	1 000 5 – 15 yr	
Childhood cancer	100 new cases per million / year	500 U5 1 000 5 - 15	<1 000
Type 1 Diabetes	10 / 100 000 new cases / year	500 U5 1 000 5 – 15	5 000
Renal Disease	12 new cases / million / year	60 new cases / yr	< 1 000
Cerebral Palsy	2 / 1 000 births	2 000 / yr	> 10 000
Epilepsy	5% have epilepsy		
Congenital disorders	6%	70 000	?

CHALLENGES - INEQUALITY

PROVINCIAL MORTALITY RATES



Provincial
District

24.0 – 49.6
16.7 – 91.3

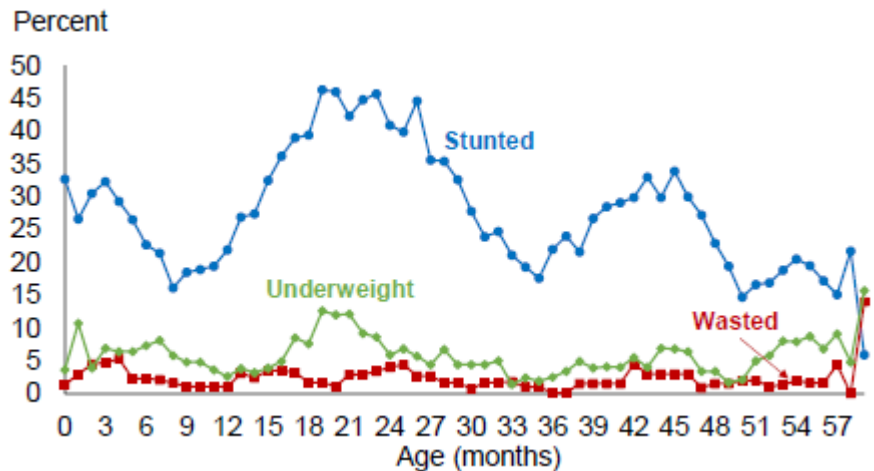
5.5x variation
2.4 x variation

CHALLENGES- URBANISATION

- Poverty
- Poor housing
- Inadequate services
- Changing diseases

- Asthma
- Malnutrition

Wasted 2.5%
 Stunted 27.4%
 Obese 13.3%

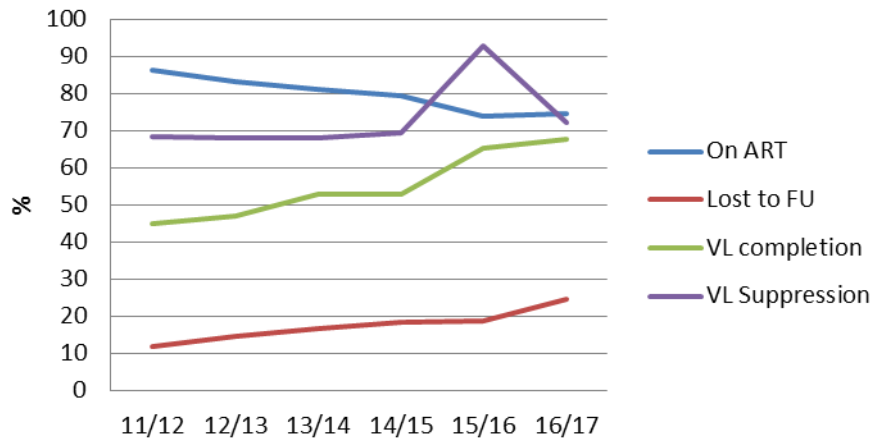


CHALLENGES - FUNDING

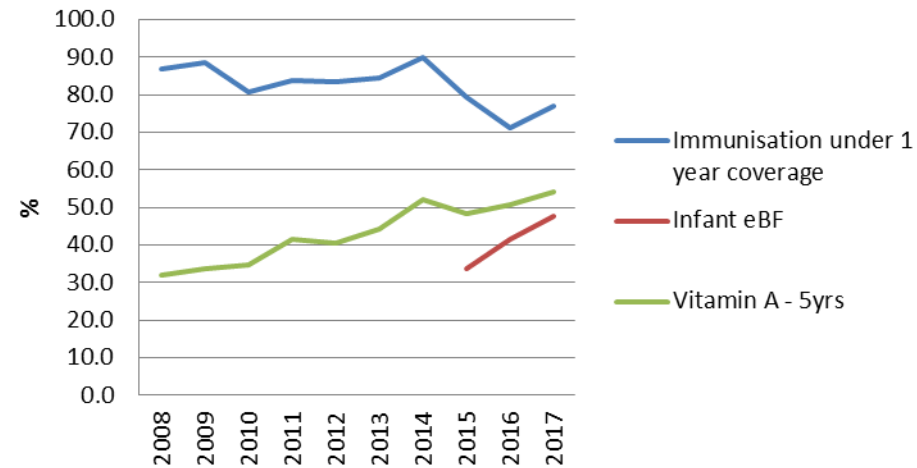
- Spending
 - 8.5% of GDP
 - 52% in private sector
 - 48 % in public sector
 - 17% medical aid cover
 - ~ 72% totally dependent on public sector
 - 78.7% of budget on CoE
- 8 provincial DoH “bankrupt”
 - Unable to appoint staff
 - Unable to maintain infrastructure
 - Unable to ensure uninterrupted supply of drugs

CHALLENGES - IMPLEMENTATION

KZN CHILD ART PROGRAMME



PROGRAMME COVERAGE



CLINICAL AUDIT SCORES

AGE	54.1%	Epilepsy	52.9%
ARI	58.5%	CP	54.8%
SAM	53.5%	Asthma	53.5%
General	55.2%		

CHALLENGES – GOVERNANCE/CARE

LEVEL	MODIFIABLE FACTOR	2012	2013	2014	2015
WARD	Lack of High Care and/or ICU facilities for children in own/higher level facility	1	1	1	1
	RTHC information not present in child's folder	2			
	Inadequate history taken in ward	3			
	Insufficient notes on clinical care in ward (assess, manage, monitor)		2		
	Inadequate investigations in ward		3		
	Other clinical personnel modifiable factor in ward			3	
	New danger signs inadequately identified while in ward			2	2
	Inadequate response to new danger signs				3
A&E	Inadequate notes on clinical care (assess, manage, monitor) at A&E	1	1	1	
	Inadequate history taken at A&E	2	2	2	
	Inadequate investigations (blood, x-ray, other) at A&E	3	3	3	
REF FACILITY	Severity of child's condition incorrectly assessed at referring facility	1	2	1	2
	No or delayed referral to higher level	2	1	2	1
	Inadequate referral letter from referring facility	3	3	3	3
CLINIC	Inadequate assessment for HIV (IMCI not used) at clinic/OPD	1	2	2	2
	Child's growth problem inadequately identified/classified	2	1	1	1
	Delayed referral for SAM, weight loss, or growth faltering	3	3	3	
	Danger signs missed at clinic/OPD				3
HOME	Caregiver delayed seeking care	1	1	1	1
	Caregiver did not recognise danger signs/severity of illness	2	2	2	2
	Child not provided with adequate (quality and/or quantity) food at home	3	3	3	3

OPPORTUNITIES

- NHI
 - Universal Health Care
 - Increased package of care for all
 - Partnership between public & private sectors
 - Ethical framework for selection of package
 - Time to establish
 - Need
 - Skills
 - Systems, processes & tools

CONCLUSION

- Limited epidemiological transformation in RSA
- Focus remains on survival
- Limited transformation of health services
- Comprehensive, holistic care is uncommon
- Need to promote “thriving”
- UHC offers an opportunity to transform healthcare
- Advocacy required to ensure inclusion of “rare diseases” in package of care