



NORTH-WEST UNIVERSITY<sup>®</sup>  
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technology innovation  
A G E N C Y

# Ethics discussion – Newborn Screening

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RareX 2016

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## Newborn Screening Status in South Africa

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# Ethics - Guiding policies

1. South African constitution
  - Equal before the law
2. UN convention on the rights of the child
  - Equal protection and benefit
  - No discrimination, stigmatization or marginalization
3. African charter on the rights and welfare of the child
  - Highest attainable standard of health
4. UN convention on the rights of persons with disabilities
  - Family environment
  - Happiness love and understanding

# Ethics – Guiding economic models

- Immediate implementation (WHO)
  - More effective, less costly
  - More effective, equal cost
  - Equal effectiveness, less costly
  - $CUA \leq GDP/Capita$  (SA  $\approx$  \$7 000  $\approx$  R90 000)

# Some costs and other stats

	Public Health Care	Private Health Care	Total
	(Per annum)		
Births	980,000	170,000	1,150,000
Affected by NBS condition	490	85	575
Cost of Screening	R 782M	R 209M	R 991M
Cost of not screening	R 722M	R 714M + R 17M	R 1453M
Cost of implementing NBS	R 60M	R 192M	R 252M
Budget	R 168B	R 140B	R 308B
NBS as % of Budget	0.04%	0.14%	0.08%
Average principle member contribution		R 36,000	
Increase to cover NBS		R 48	
% Increase		0.13%	

# What about cost utility analysis

	Public Sector	Private Sector	Weighted Average
No screening	38,000	189,000	68,000
Screening	23,000	35,000	25,000

# Cost of care - Financial support/insurance

- Income < R 180 000 (single) or < R 360 000 (married)
  - < 18yrs □ Care dependency grant R 1 510
  - > 18yrs □ Disability grant R 1 510
- Higher income (? On medical aid)
  - No support from government or scheme
    - Apologies to Discovery Health and Camaf

Why are we not screening our children?  
(like the rest of the developed and developing world)