WHO GUIDANCE ON TB PATIENT COST SURVEYS

17 July 2024

Nkateko Mkhondo (NPO TB)
WHO

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KEY GLOBAL INDICATORS, MILESTONES AND TARGETS FOR THE END TB STRATEGY

Vision:

A world free of TB

Zero TB deaths,
Zero TB disease, and
Zero TB suffering

Goal:

End the Global TB epidemic

	MILESTONES		TARGETS	
			SDG*	END TB
	2020	2025	2030	2035
Reduction in number of TB deaths compared with 2015 (%)	35%	75%	90%	95%
Reduction in TB incidence rate compared with 2015 (%)	20%	50%	80%	90%
TB-affected families facing catastrophic costs due to TB (%)	0%	0%	0%	0%

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TB PATIENT COST SURVEYS

- In 2015, WHO convened a taskforce to develop a generic protocol and instrument for TB patient cost surveys.
- Several pathfinding countries implemented their national surveys by 2017, which provided valuable feedback to revise the protocol
- In 2017, the protocol was published as *TB Patient Cost Survey: a handbook*

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SURVEY OBJECTIVES

1. **To document the magnitude and main drivers of different types of costs incurred by TB patients (and their households) in order to guide policies to reduce financial access barriers and minimize the adverse socioeconomic impact of TB.**
2. To determine the baseline and periodically measure the percentage of TB patients (and their households) treated in the NTP network who incur catastrophic total costs due to TB.
3. Determine the correlation between facing costs above different thresholds of annual household income and dissaving, in order to assess if the measure of dissaving is a sufficient metric of catastrophic costs
4. Determine the association between cost and treatment outcome

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BASIC DESIGN

- Facility-based patient survey: **national sample of patients on treatment** - all consecutive patients on TB treatment in sampled facilities
- National sample: 500-1000 patients (min. 20 clusters)
- Costs typically: $25,000 - $80,000
- Survey frequency: once every 5 years
- Cross sectional study with retrospective data collection and projections
- Questionnaire (130 questions - 40-60 mins long): 28 questions directly from treatment card, rest to complete depending on treatment type or phase
- Projections based on data collected from other patients
- Field testing version requests adaptation but does not delete any questions

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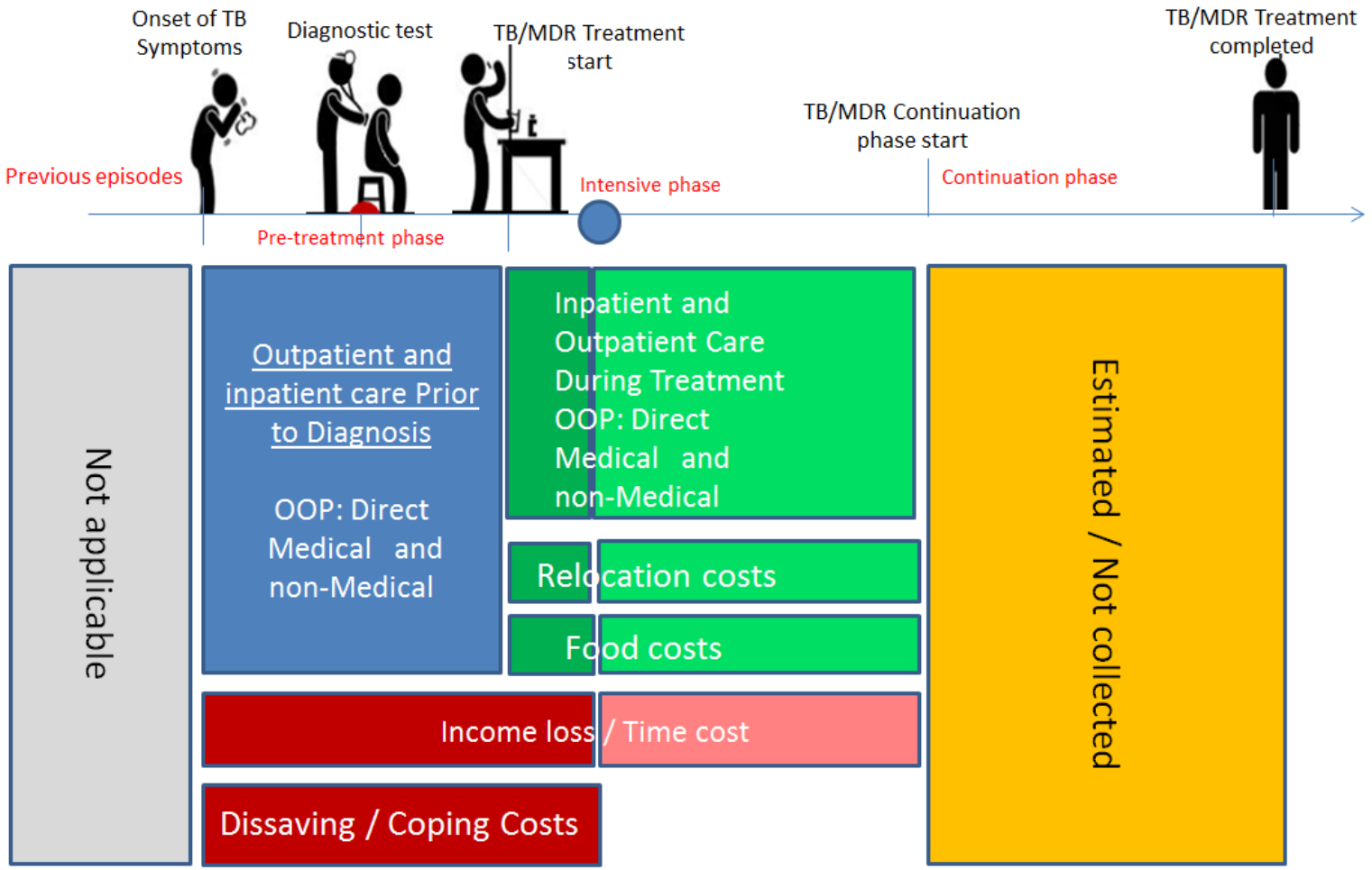
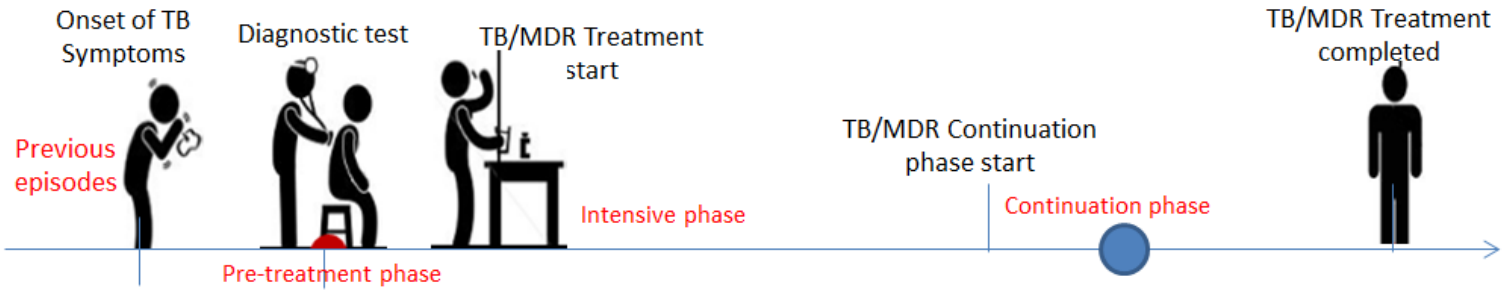
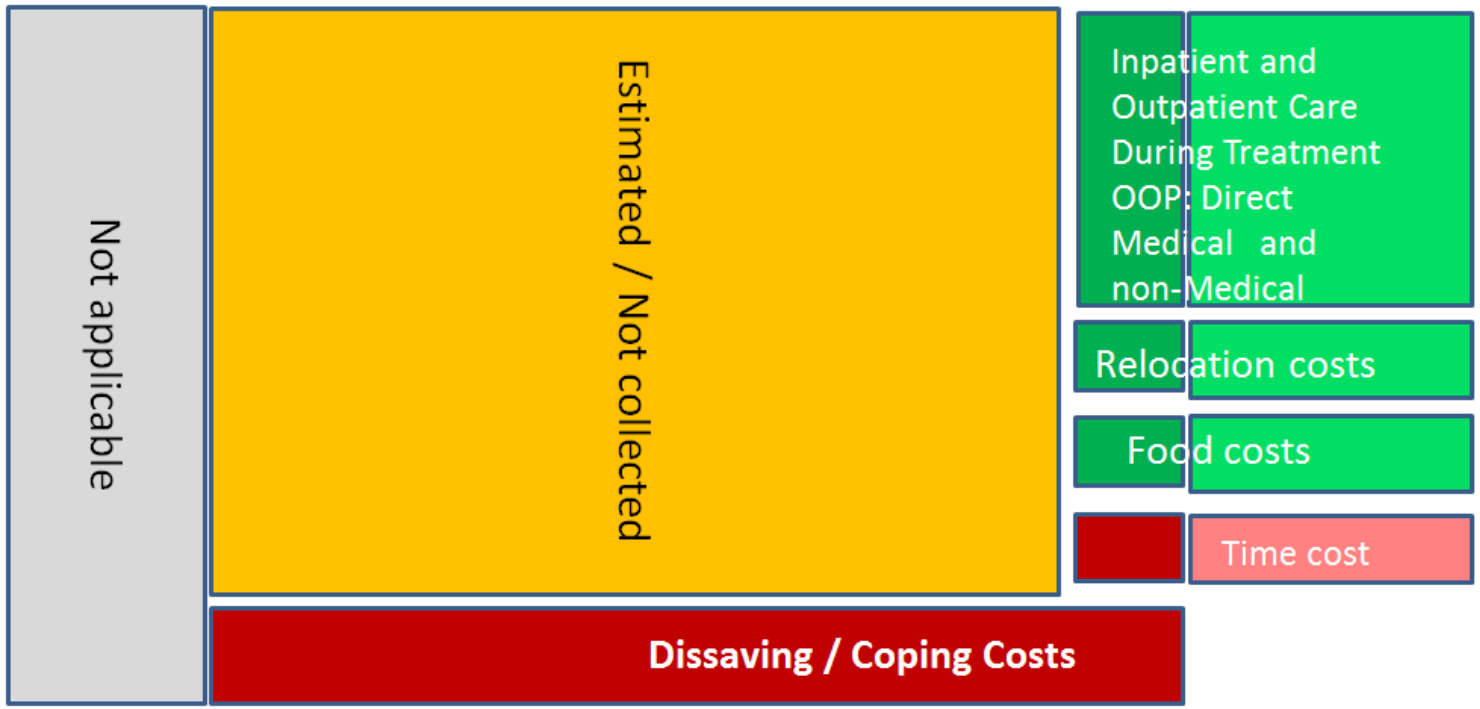
INTENSIVE PHASE

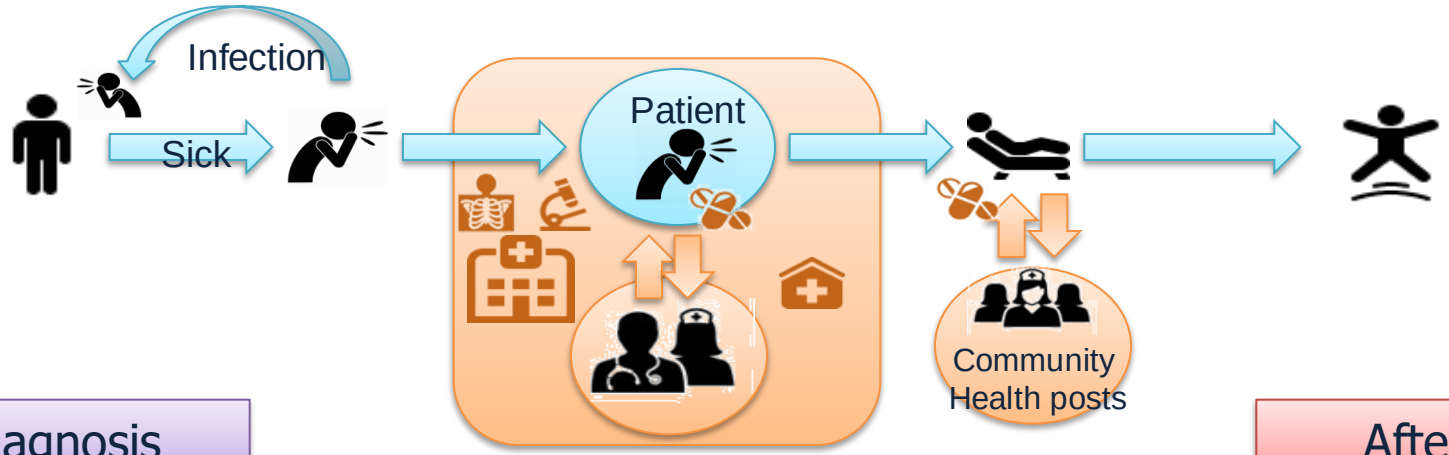


CONTINUATION PHASE





PATIENT COSTS COMPONENTS ALONG THE PATIENT PATHWAY



Before TB diagnosis

- UHC for general medical coverage
- Streamline patient pathways (service decentralization, engaging all providers, innovative technologies for early diagnosis)
- Systematic TB screening including contact investigation

After TB diagnosis

- Enhancing TB care financing within UHC policies (including free TB care policies)
- Service/benefit package design
- Adopting innovative approaches

- TB specific support for non-medical cost
- Social assistance schemes
- Service decentralization

- Income compensation (e.g. sickness insurance)
- Social assistance schemes (e.g. disability grant)
- Address stigma and discrimination / legal protection

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- Types of costs:
  - Direct medical (X-rays, medicine, doctor's fees, etc.)
  - Direct non-medical (food, travel, accommodation, etc.)
  - Time/Income lost by patient and caregiver (net of welfare payment)
  - Household assets
  - Coping measures

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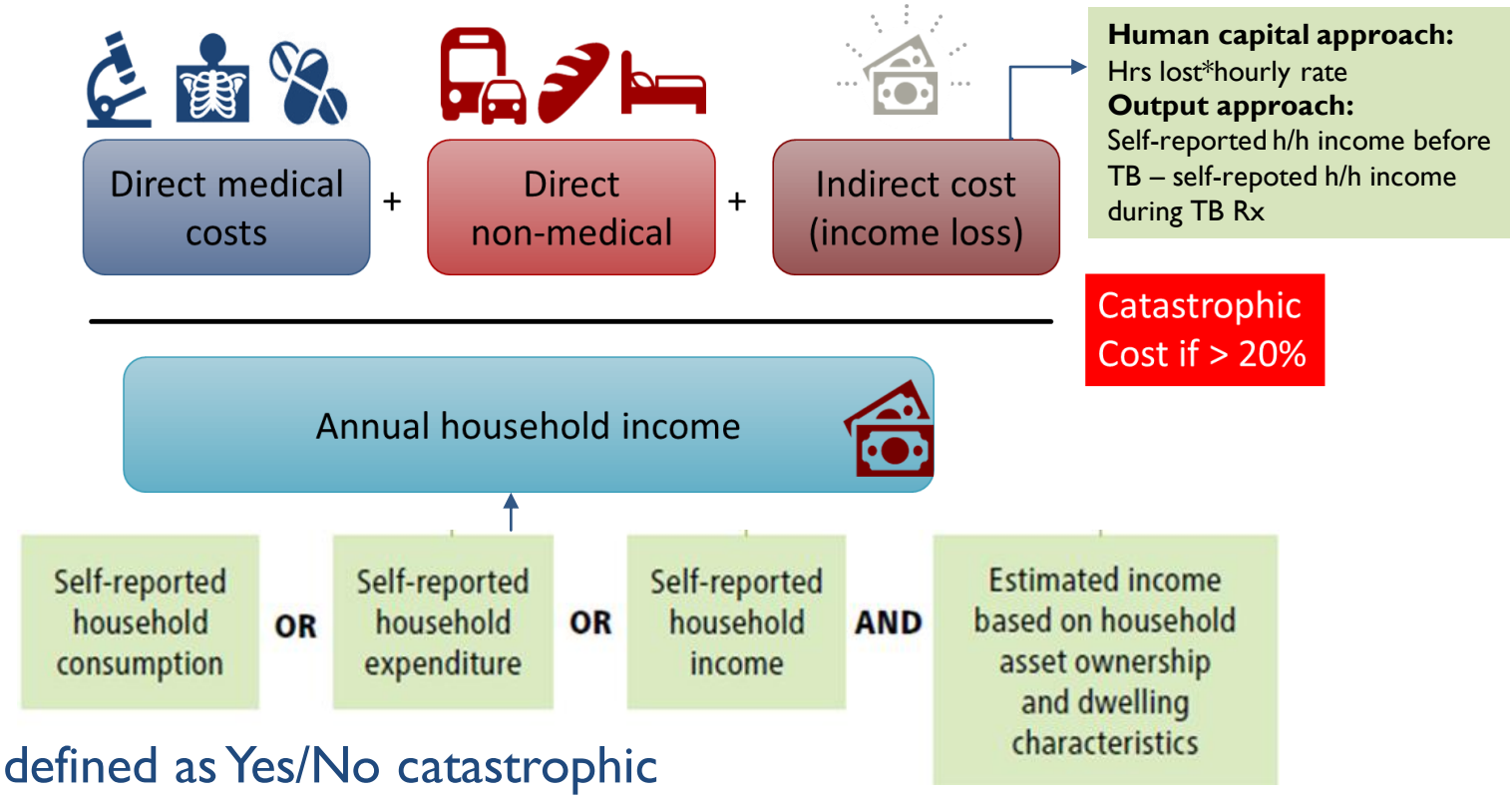
END TB STRATEGY INDICATOR

- Costs are defined as catastrophic if:



- Each household will be defined as Yes/No catastrophic
- We then report the percentage of households who are catastrophic and adjust to obtain a national estimate

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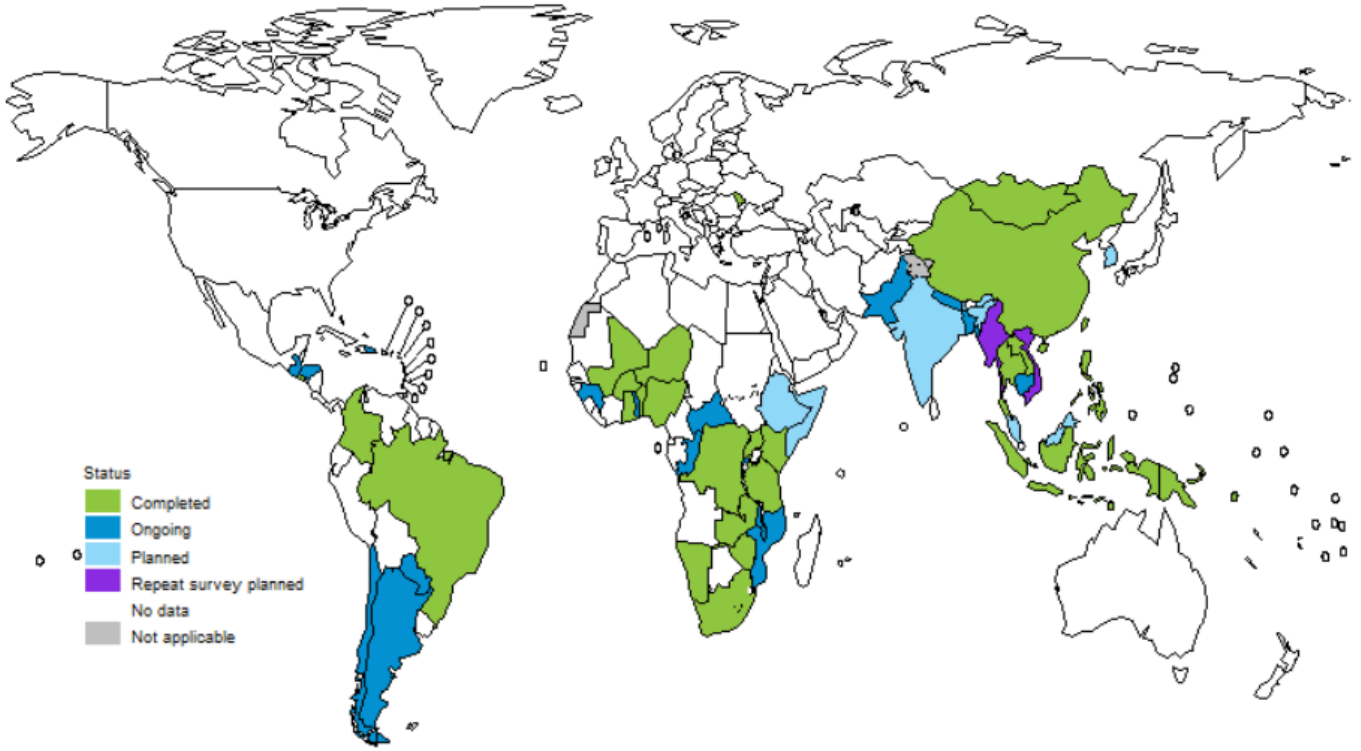
STATUS OF NATIONAL SURVEYS OF COSTS FACED BY TB PATIENTS AND THEIR HOUSEHOLDS SINCE 2015



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WHY THE FOCUS ON ECONOMIC BURDEN?

- Many TB patients suffer from a huge economic burden (even under a free-treatment policy)
- Economic burden of patients and families:
  - Barrier to early diagnosis
  - Causes treatment interruption and loss to follow up
  - Further impoverishes patients and families and increase vulnerability to TB
- Surveys on the economic burden of patients can provide valuable information to improve the delivery of TB care
- Increased disease transmission and drug-resistance:
  consequences are beyond individual level

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THE BIGGER PICTURE…

UHC / Health care delivery

- Effective interventions
- Free-of-charge care
- Appropriate technology
- Patient-friendly delivery

Social protection

- Sickness insurance
- Disability grants
- Travel vouchers
- Food package
- Other cash transfer
- Job security
- Housing support
- Other welfare grants

Reduce or compensate direct and indirect costs

Protect against economic burden of TB

% with catastrophic total cost of TB

↓

Other outcomes

- Reduced TB risk - prevention
- Improved access & case detection
- Improved TB treatment outcomes

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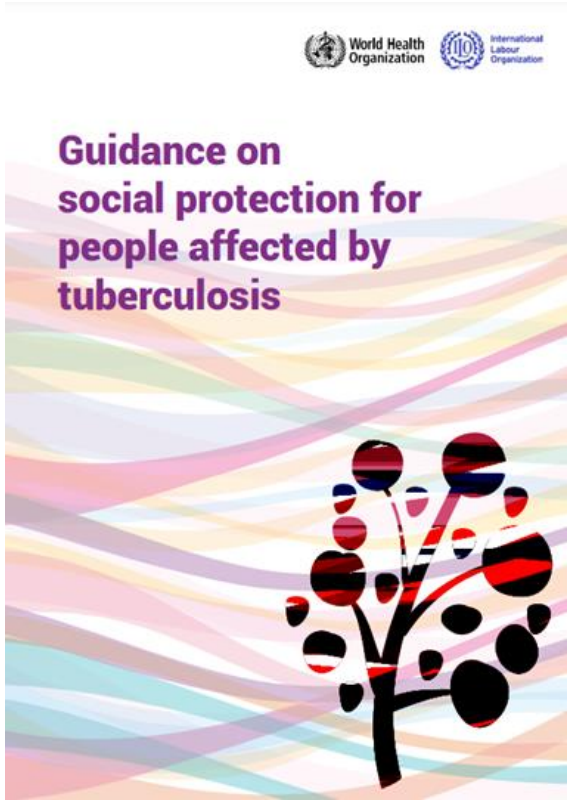
Epidemiological impact

Reduced TB prevalence, incidence and death rate



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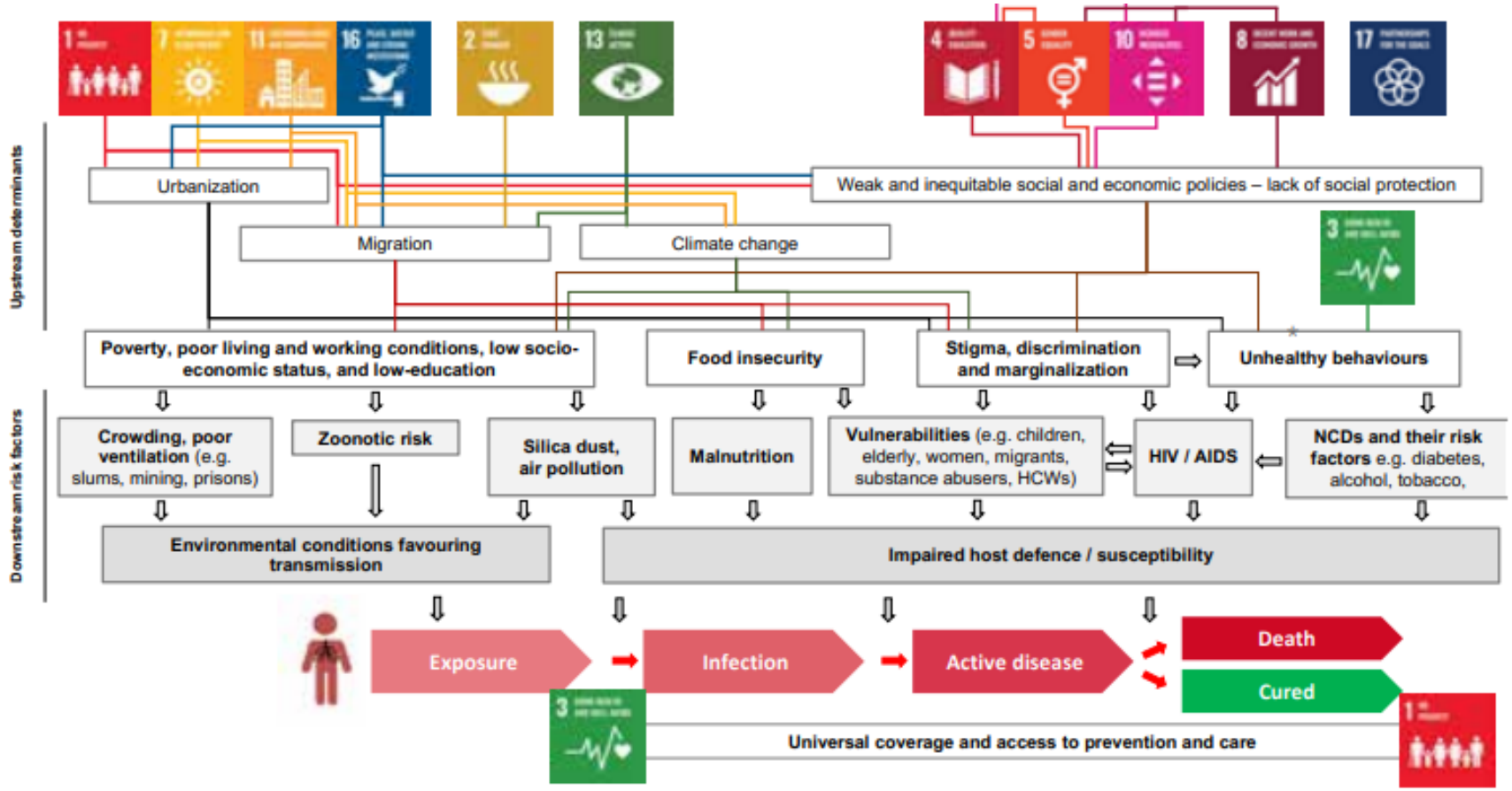
SOCIAL PROTECTION IN THE 2030 AGENDA FOR SUSTAINABLE DEVELOPMENT



END TB

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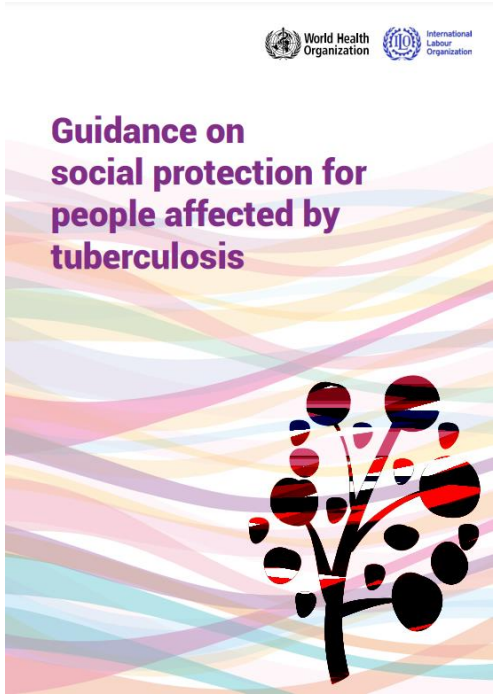
THANK YOU!



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FINDINGS FROM SOUTH AFRICA`S FIRST NATIONAL PATIENT COST SURVEY

17 July 2024

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OUTLINE OF PRESENTATION

- Background & Methodology
- National TB Patient Cost Survey: Summary Findings and Results
- Recommendations & Implications for TB care
- Way forward

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BACKGROUND & METHODOLOGY

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BACKGROUND

- South Africa has a high TB burden worsened by poverty and inequality.
- Despite free treatment, TB patients still incur significant costs, highlighting the need to understand these financial burdens
  - These costs are incurred **directly** through out-of-pocket payments for ***medical expenses*** outside the public health system & non-medical payments for travel, food, caregiving etc.
  - Cost are also incurred **indirectly** as opportunity costs of time losses or income loss while seeking treatment
- These high TB costs can lead to;
  - Financial hardship and impoverishment
  - Poor treatment outcomes and risk of relapse
  - Household economic instability as they displace day-to-day needs to take of TB related costs
- This survey can inform policies to reduce TB's financial impact and support global efforts to understand and alleviate the impact of patient costs on TB patients.

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METHODOLOGY

- Cross-sectional survey design
- We followed the guidelines of the 2017 Tuberculosis Patient Cost Surveys Handbook
- The handbook provides countries with a standardised, approach to collecting, analysing and reporting patient cost data
- Wits HREC (Medical approval): **M190469** granted in 2019

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SURVEY PREPARATIONS

- Multisectoral approach with representatives of various government and private organisations constituting a technical advisory group (TAG)
  - World Health Organization (WHO)
  - **Government**
    - National Department of Health (South Africa)
    - South African Social Security Agency (SASSA)
    - Department of Social Development (South Africa)
  - **Partners/Organizations**
    - **FUNDER:** United States Agency for International Development (USAID)
    - Health Economics and Epidemiology Research Office (HE2RO)
    - Clinton Health Access Initiative (CHAI)
    - London School of Hygiene & Tropical Medicine (LSHTM)
    - Médecins Sans Frontières (MSF)
- The protocol was jointly developed by TAG and regular meetings we conducted before, during and after the survey.

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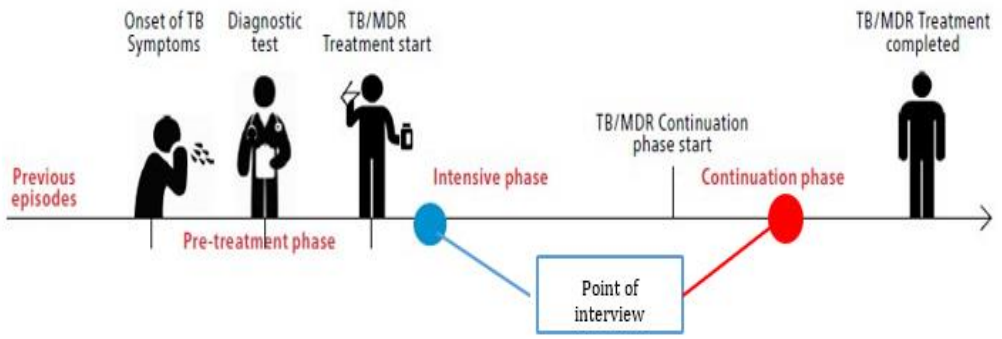
DATA COLLECTION



N/A	Data collected	Costs will be extrapolated for the remaining period	Data not collected, these costs will be estimated

- Aurum contracted for data collection
- Data collected from **Mar 2020 to Dec 2020**
  - This was during the COVID-19 pandemic
  - We initially planned to collect data from clinics, but patients were not always available, so we visited their homes for data collection
- Data were collected for patients in both intensive & continuation phases
  - 2 weeks in the intensive phase
  - 4 weeks in the continuation phase
- Segments of uncollected data were extrapolated
  - e.g. continuation phase data for intensive phase patients were extrapolated using data collected for intensive phase patients

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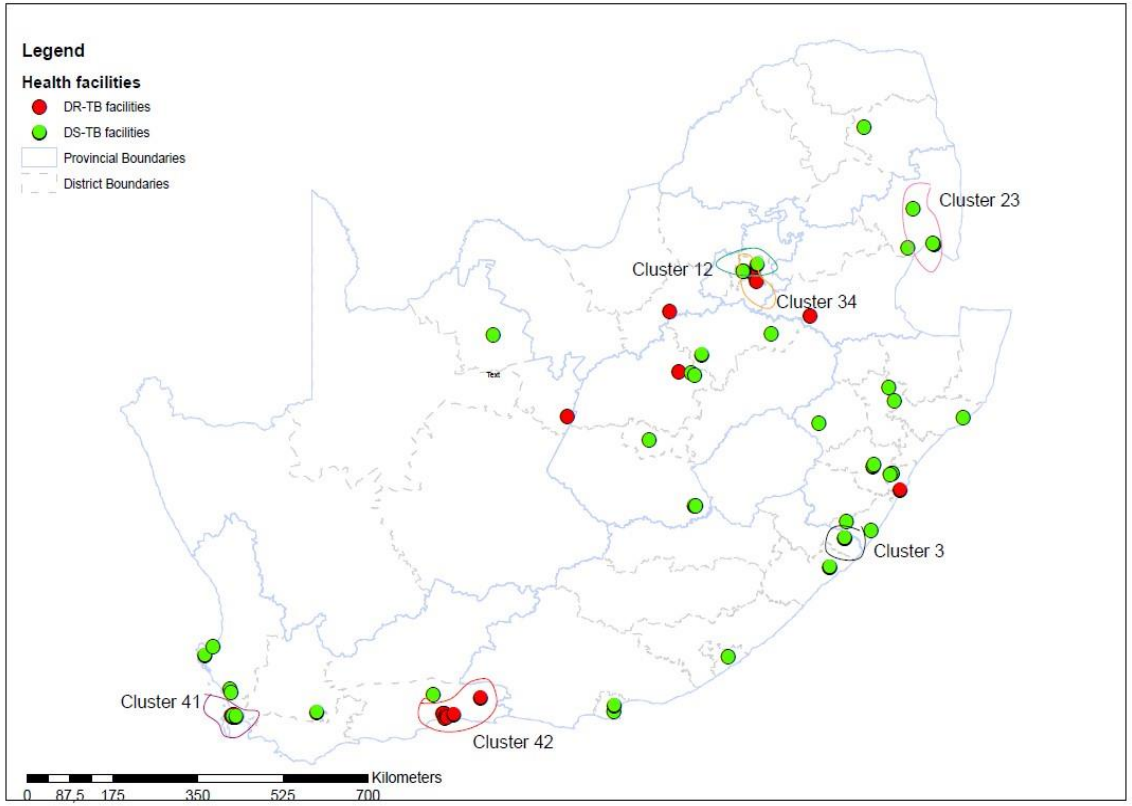
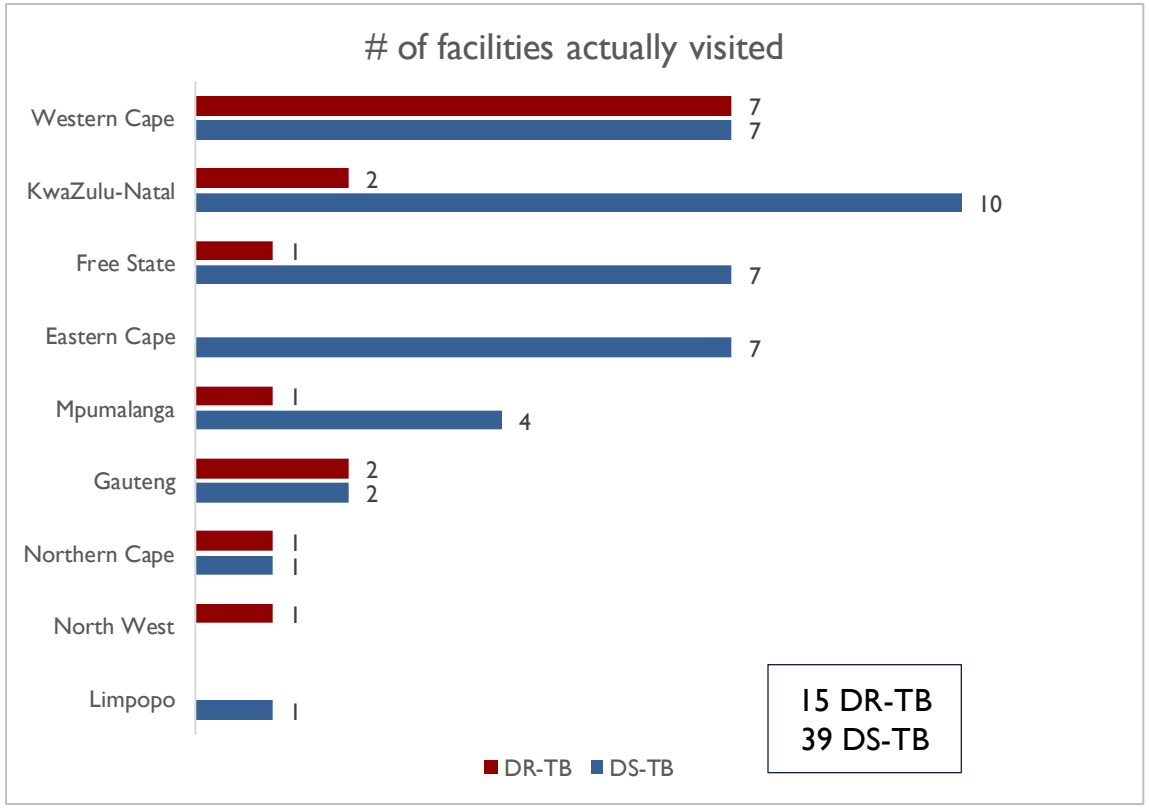
GEOGRAPHICAL SPREAD (42 CLUSTERS, 68 FACILITIES)





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RECAP: DEFINITIONS OF KEY TERMS

- **Direct Costs:** Out-of-pocket expenses for medical services and essential non-medical needs during TB treatment.
  - ***Medical:*** Consultations, medications, diagnostics, hospital stays.
  - ***Non-medical:*** Transportation, special foods, nutritional supplements.
- **Indirect Costs:** Wages lost and missed economic opportunities mainly due to illness-related inability to work.
- **Catastrophic Costs due to TB:** Direct and indirect costs that exceed 20% of a household's pre-TB annual income, significantly impacting living standards. A crucial indicator in the End TB strategy.
  - $\frac{direct\ costs + indirect\ costs}{Household\ pre{-}TB\ Annual\ income}$

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CATASTROPHIC COSTS – *FURTHER DETAILS*

What Makes TB Costs Catastrophic

- **High Out-of-Pocket Expenses**
  - Frequent trips to health facilities.
  - Additional costs for medications, special foods, and vitamins.
- **Significant Income Loss**
  - Patients unable to work during illness.
  - Family members lose income while caregiving.
- **Long Treatment Duration**
  - Ongoing expenses, especially for drug-resistant TB.
- **Lack of Financial Protection**
  - No insurance to cover extra costs.
  - Limited government support or social safety nets.

Why TB Costs Are Catastrophic

- **Financial Hardship:** Forced to choose between basic needs like food, education, and healthcare.
- **Debt and Asset Depletion:** Borrowing money or selling belongings leads to long-term instability.
- **Poverty:** High costs push households deeper into poverty.
- **Economic Instability:** Continuous expenses destabilise household finances.
- **Poor Health Outcomes:** Inability to afford worsens health.
- **Social Impact:** Isolation and reduced quality of life.

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RESULTS


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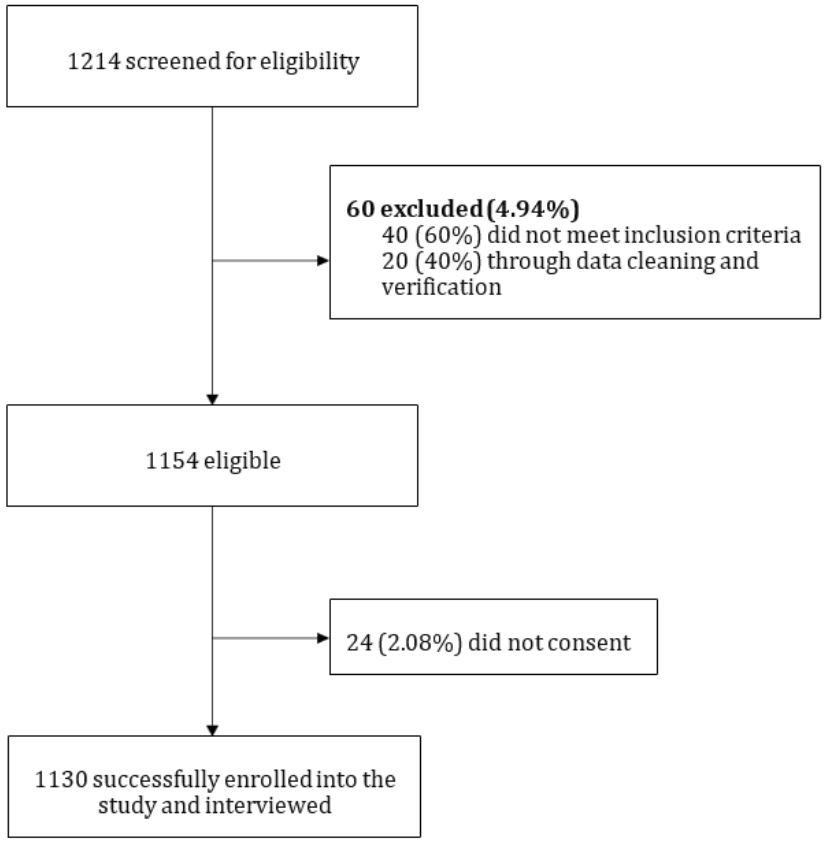
DEMOGRAPHICS



Demographic characteristics	DS-TB		DR-TB	
	N	(%)	N	(%)
Total	930		200	
Sex				
Female	539	58.0%	128	64.0%
Male	389	41.8%	72	36.0%
(Missing)	2	0.2%	0	0.0%
Age group				
0–14	43	4.6%	1	0.5%
15–24	114	12.3%	25	12.5%
25–34	259	27.9%	54	27.0%
35–44	226	24.3%	63	31.5%
45–54	141	15.2%	40	20.0%
55–64	92	9.9%	15	7.5%
≥65	55	5.9%	2	1.0%
Education level				
No education	121	13.0%	22	11.0%
Up to grade 7	163	17.5%	32	16.0%
Grade 8-11	411	44.2%	89	44.5%
Completed grade 12 or higher	233	25.1%	57	28.5%
(Missing)	2	0.2%	0	0.0%
Employment status				
Full-time	220	23.66%	58	29%
Part-time, occasional, seasonal	135	14.52%	21	10.5%
Unemployed	432	46.45%	104	52%
Student, homemaker, other	135	14.52%	15	7.5%
(Missing)	8	.86%	2	1%

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CLINICAL CHARACTERISTICS

Clinical characteristics	DS-TB		DR-TB	
	N	(%)	N	(%)
Total	930		200	
Treatment phase				
Intensive phase	407	43.8%	122	61.0%
Continuation phase	523	56.2%	78	39.0%
Treatment category				
New	792	86.9%	160	80.0%
Relapse	59	6.5%	10	5.0%
Retreatment	50	5.5%	28	14.0%
Unknown	10	1.1%	2	1.0%
HIV status				
Positive	442	47.5%	119	59.5%
Negative	408	43.9%	52	26.0%
Unknown	80	8.6%	29	14.5%
Type of TB				
Bacteriologically confirmed pulmonary TB	771	83.0%	162	83.1%
Clinically diagnosed pulmonary TB	12	1.3%	8	4.1%
Extrapulmonary TB	146	15.7%	25	12.8%
Diagnostic delay (>4weeks) *	106	31.4%	36	35.0%

- We interviewed more DS-TB patients in the continuation and more DR-TB in the intensive phase
  - This is just due to the patients we found at the time
- More than 11% of the patients were either relapse or retreatment
- About 60% of DR-TB patients were HIV +ve while for DS-TB, about half were positive
- DS-TB patients had a mean diagnostic delay of up to 106 days

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TIMES LOSSES (OPPORTUNITY COSTS)

	N*	DS-TB		DR-TB		All TB patients		P-value
		Number	(95% CI)	Number	(95% CI)	Number	(95% CI)	
Number of facility visits		Visits		Visits		Visits		
Pre-disease	529	1.0	(0.9–1.0)	1.1	(1.0–1.2)	1.0	(0.9–1.0)	0.091
Directly observed treatment	986	2.0	(0.9–3.1)	55.3	(26.1–84.4)	3.9	(1.9–5.9)	0.001
Drug pickup	1,128	9.4	(7.5–11.4)	8.8	(0.4–17.1)	9.4	(7.5–11.3)	0.877
Medical follow-up	1,115	11.7	(10.7–12.6)	21.8	(15.6–28.0)	12.0	(11.0–13.0)	0.003
Total number of facility visits	1,130	23.2	(20.7–25.7)	79.4	(60.6–98.2)	25.2	(22.3–28.0)	<0.001
Hours lost by patient		Hours		Hours		Hours		
Pre-disease	447	3.5	(2.7–4.3)	3.3	(2.5–4.1)	3.5	(2.8–4.2)	0.705
Hospitalization	1,130	17.6	(2.2–33.1)	245.1	(67.3–423.0)	25.3	(8.4–42.3)	0.017
Directly observed therapy	977	2.0	(0.3–3.8)	27.5	(-7.9–62.9)	2.9	(0.7–5.1)	0.167
Drug pickup	784	23.1	(18.7–27.6)	56.2	(42.4–70.0)	23.6	(19.2–28.0)	<0.001
Medical follow-up	1,129	22.0	(17.4–26.7)	30.1	(16.9–43.4)	22.3	(17.8–26.8)	0.263
Total lost time	1,130	61.5	(44.4–78.6)	319.5	(160.2–478.8)	70.3	(51.8–88.7)	0.003
Hours lost by caregivers		Hours		Hours		Hours		
Hospitalization	1,029	11.0	(0.6–21.4)	18.2	(2.6–33.7)	11.3	(1.3–21.3)	0.457
Directly observed therapy	1,127	0.7	(-0.5–2.0)	0.0	(0.0–0.0)	0.7	(-0.5–1.9)	0.253
Drug pickup	1,060	3.9	(2.4–5.5)	1.4	(-0.6–3.3)	3.8	(2.4–5.3)	0.050
Medical follow-up	1,062	2.9	(1.6–4.2)	0.9	(0.0–1.9)	2.9	(1.6–4.1)	0.020
Total lost time	1,130	17.1	(6.1–28.0)	19.6	(3.5–35.6)	17.2	(6.6–27.8)	0.801

- Health facility visits were generally high, but DR-TB required 3 times more visits
- Like visits, DR-TB patients lost more time but mainly due to hospitalisation
- Caregivers also lost time due to taking care of TB patients
- Calculating losses based on an 8-hour working day;
  - DS-TB – 7.7 days lost
  - DR-TB – 40 days lost
  - Caregivers – 2 days lost
- These losses translate into indirect costs, impacting the economic well-being of patients and their families.

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TOTAL EPISODE COSTS (ZAR)

TB Patient Costs, ZAR			Patients with DS-TB			Patients with DR-TB			All TB Patients		
			Mean	Median	IQR	Mean	Median	IQR	Mean	Median	IQR
Before TB diagnosis	Direct medical costs		62	0	(0-0)	12	0	(0-0)	60	0	(0-0)
	Direct non-medical costs		42	20	(0-20)	30	20	(0-20)	41	20	(0-20)
	Total direct costs		103	20	(10-20)	43	20	(0-20)	101	20	(5-20)
After TB diagnosis	Direct medical costs		530	0	(0-0)	450	0	(0-0)	527	0	(0-0)
	Direct non-medical costs	Travel	505	60	(0-631)	842	0	(0-850)	516	60	(0-644)
		Accommo-dation	15	0	(0-0)	43	0	(0-0)	16	0	(0-0)
		Food	181	0	(0-167)	200	0	(0-0)	182	0	(0-167)
		Nutrition supplement	1549	0	(0-1732)	1927	0	(0-0)	1562	0	(0-1732)
Total direct medical costs			592	0	(0-100)	462	0	(0-0)	587	0	(0-86)
Total direct non-medical costs			2292	751	(20-2941)	3043	680	(20-3225)	2317	751	(20-2941)
Income loss			6078	6	(0-1200)	14399	9	(0-13500)	6361	6	(0-1500)
Total cost (output approach)			8962	1594	(246-9150)	17904	2079	(39-18780)	9266	1600	(222-9211)

- DR-TB patients incur higher costs than DS-TB.
- Mean total DR-TB costs are double those of DS-TB.
- Indirect costs (income loss) are the main cost driver:
  - DS-TB: 68% (6078/8962)
  - DR-TB: 80% (14399/17904)
- Nutritional supplements are major drivers for direct costs.
  - Items include vitamins and immune boosters recommended by peers and relatives.

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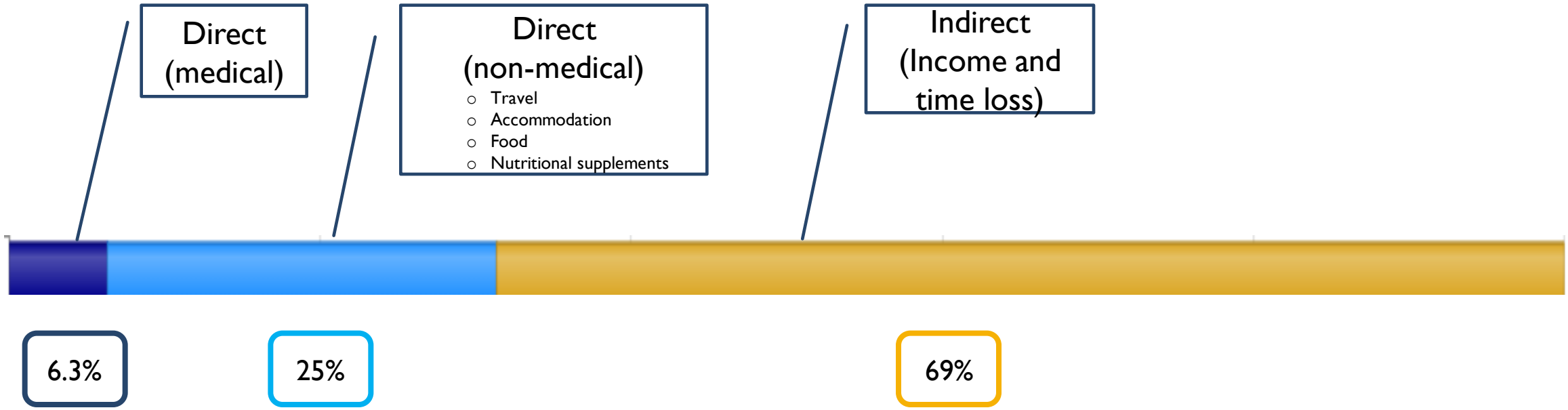
DISTRIBUTION OF COSTS INCURRED



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PATIENT AND HOUSEHOLD INCOME (ZAR)

	Patients with DS-TB		Patients with DR-TB		All TB Patients		P-value
	Mean	(95% CI)	Mean	(95% CI)	Mean	(95% CI)	
Self-reported monthly Income (in ZAR): before onset of TB symptoms, mean (95% CI)							
Individual patient	1656	(1327-1985)	2256	(1556-2956)	1676	(1357-1995)	0,136
Household	3203	(2579-3828)	3010	(2212-3808)	3197	(2592-3802)	0,71
Self-reported monthly income (in ZAR): at the interview, mean (95% CI)							
Individual patient	920	(621-1220)	1034	(495-1574)	924	(634-1214)	0,719
Household	2725	(2212-3238)	1926	(1226-2625)	2699	(2202-3196)	0,079
Impoverishment: TB-affected households below poverty line, percentage (95% CI) PPP adjusted							
Before onset of TB symptoms	93	(88.4-96.5)	87	(74.5-95.7)	93	(88.5-96.2)	0,719
At the interview	95	(90.1-98.4)	90	(80.6-96.6)	95	(90.2-98.1)	0,0786

- Patient and household incomes were already very low before TB diagnosis and worsened significantly after.
- For context, South Africa's minimum wage in 2020 was approximately ZAR 3,500 per month.
  - *Both patient and house income are lower than this minimum*
- Mean individual income plummeted by 44.9%, from ZAR 1,676 before symptoms to ZAR 924 at the interview, further aggravating the financial strain.
- Household income fell by 15.6%, from ZAR 3,197 to ZAR 2,699.
  - The smaller decrease in household income indicates that patients are somewhat shielded from complete financial ruin by other household members' incomes.
  - It is thus equally important to protect these household incomes to prevent further financial collapse.

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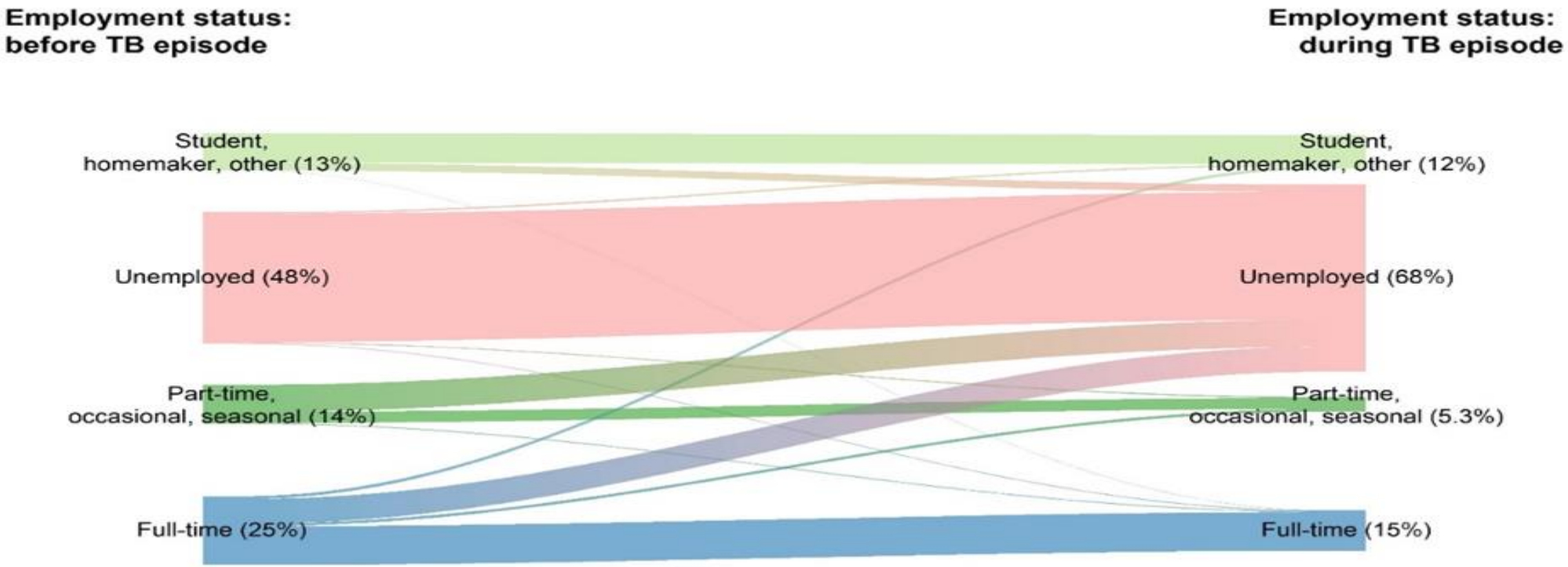
IMPACT OF TB ON EMPLOYMENT STATUS



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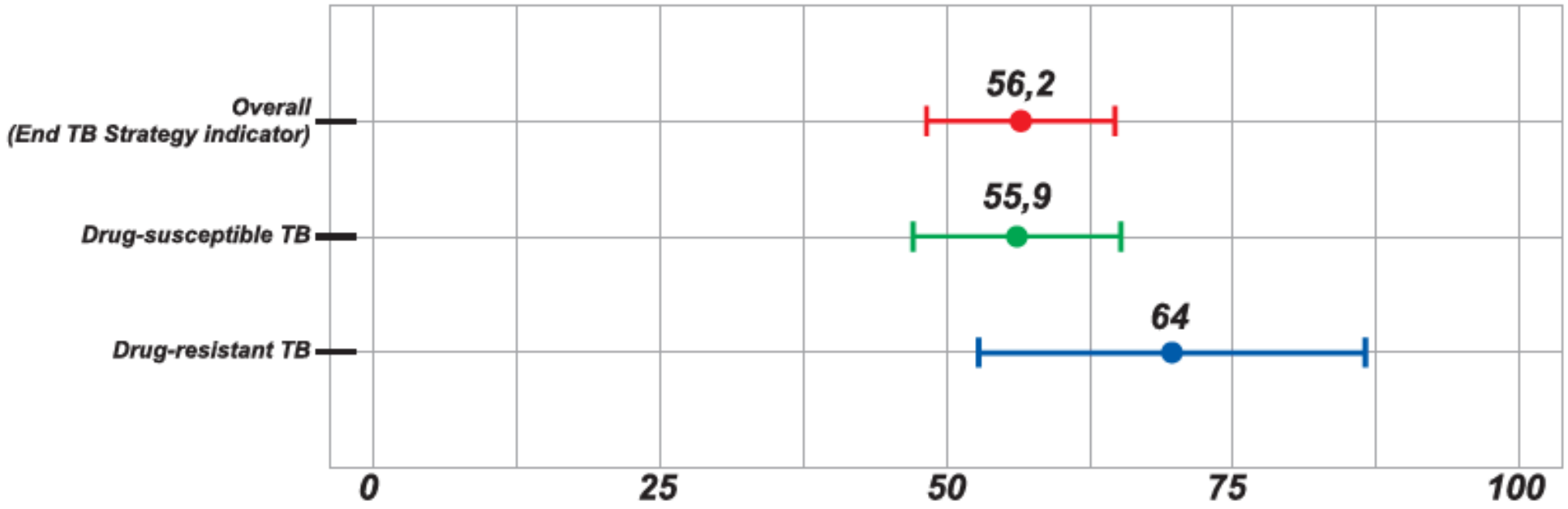
PERCENTAGE OF TB-AFFECTED HOUSEHOLDS FACING CATASTROPHIC COSTS (USING THE 20% THRESHOLD)



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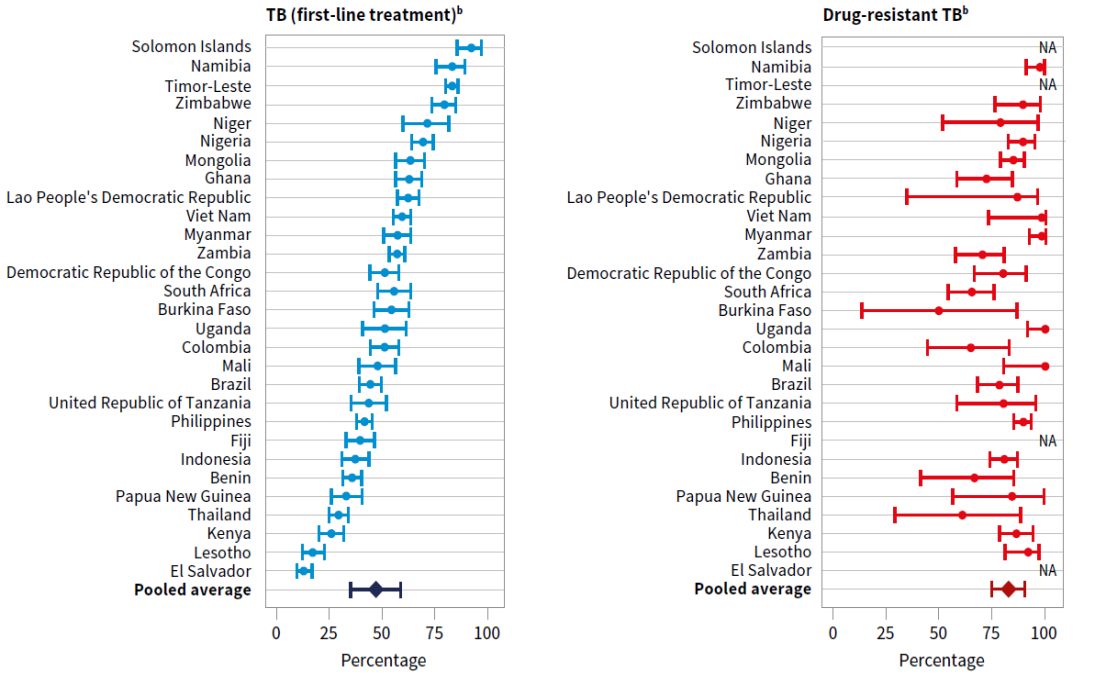
GLOBAL COMPARISONS

FIG. 36

Estimates of the percentage of TB patients and their households facing catastrophic total costs,[a] national surveys completed 2015–2022



- **DS-TB:** South Africa's catastrophic cost estimate is around 45-50% placing it in the middle range among surveyed countries.
  - Can be compared to Zambia, DRC and Burkina Faso.
- **DR-TB:** Approximately 70-75% of DR-TB patients in South Africa face catastrophic costs also placing in the middle range like DRC, Burkina Faso, Uganda
- The pooled average is around 50% for DS-TB and 80% for DR-TB.
  - South Africa's estimates are close to the global average for DS-TB (56% vs 50%) and below for DR-TB (64% vs. 80%)

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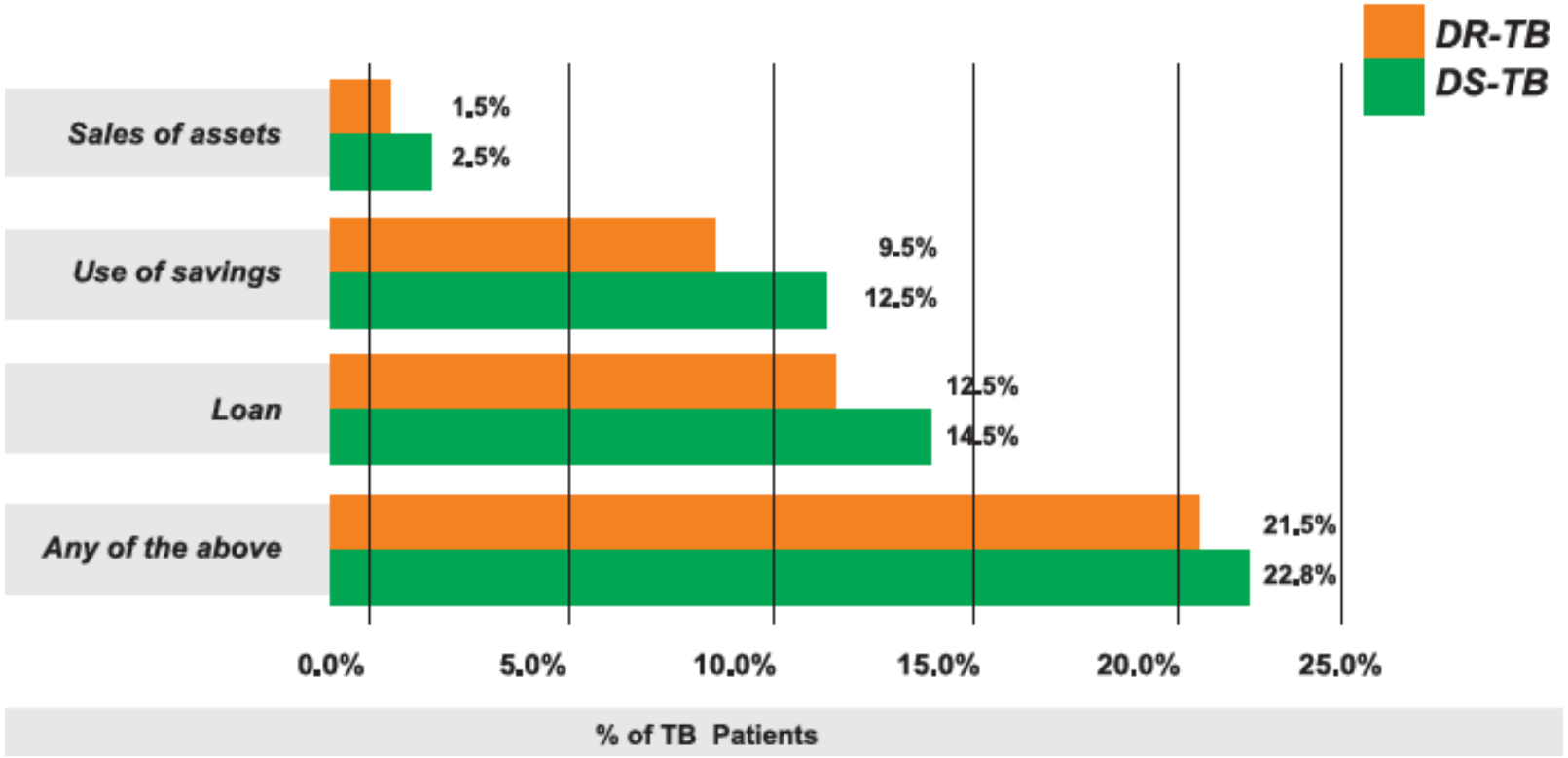
COPING MECHANISMS



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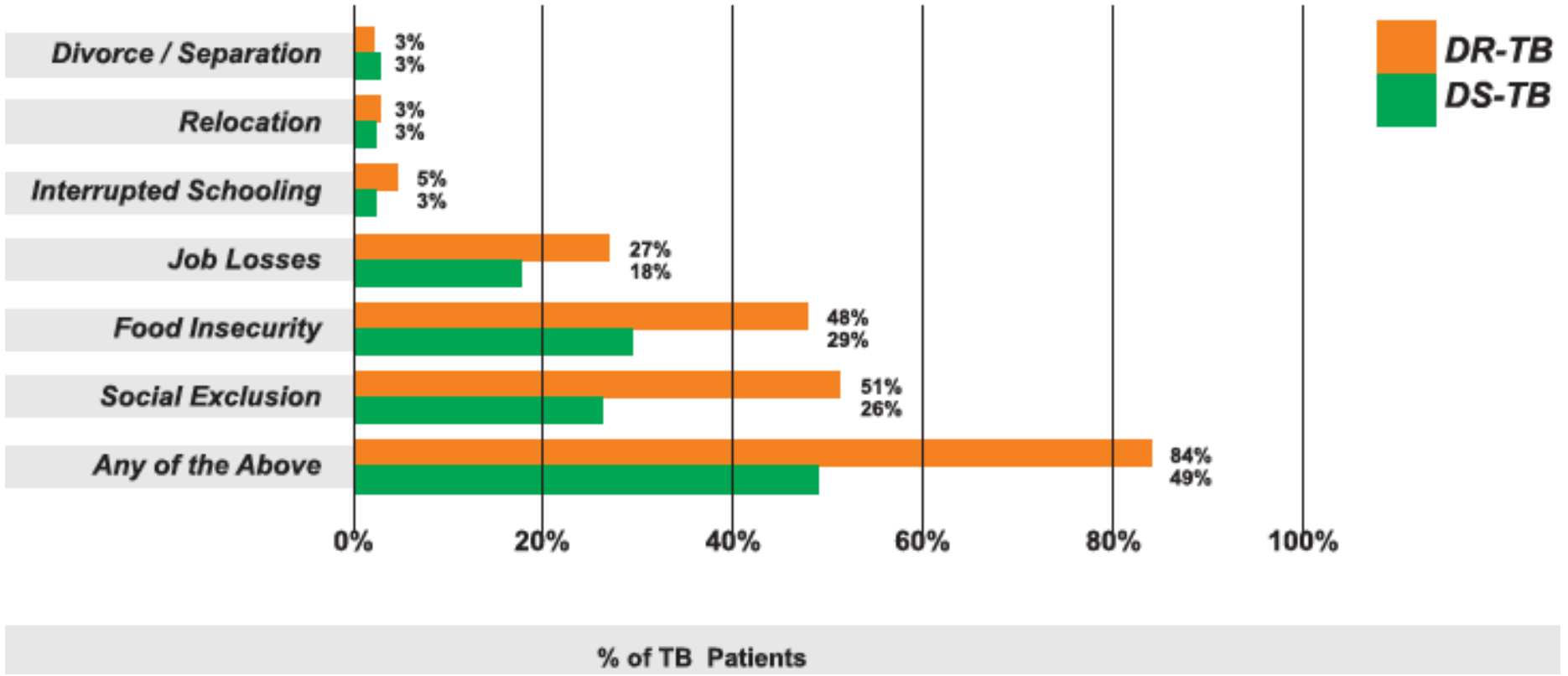
SOCIAL CONSEQUENCES



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SOCIAL SUPPORT AND IMPOVERISHING EFFECT OF TB

95.8% did not have any health insurance

33% accessed social assistance
(33% DS-TB, 20% DR-TB)

6% received food parcels

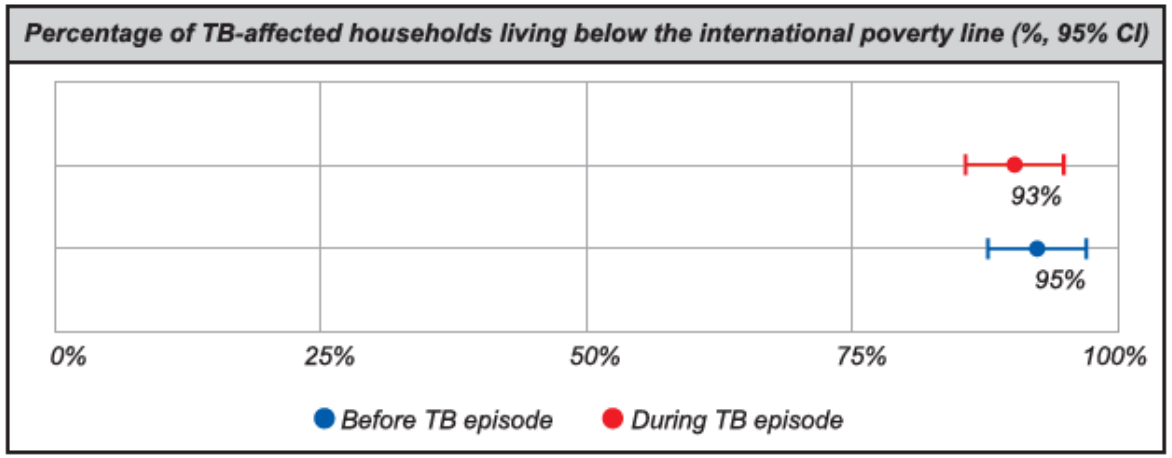

Figure 10: Percentage of TB-affected households living below international poverty line (%, 95% CI)

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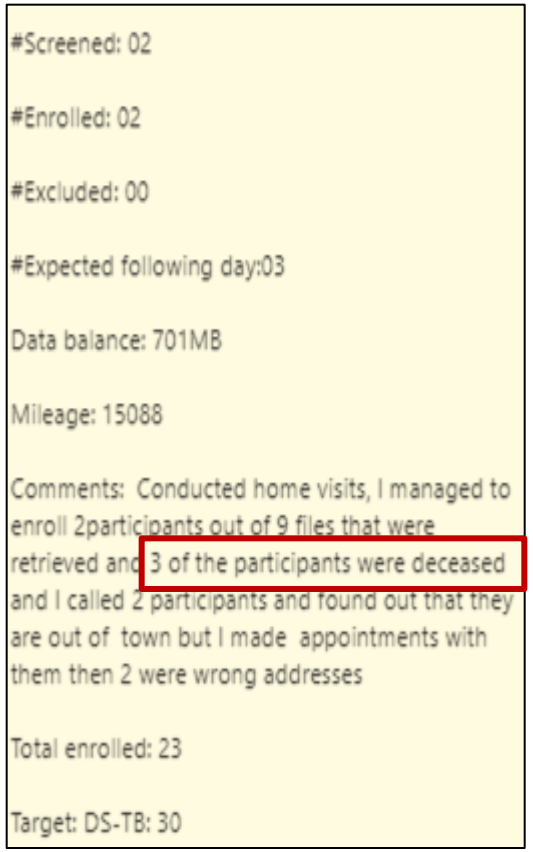
LESSONS: LONG TRAVELLING DISTANCES

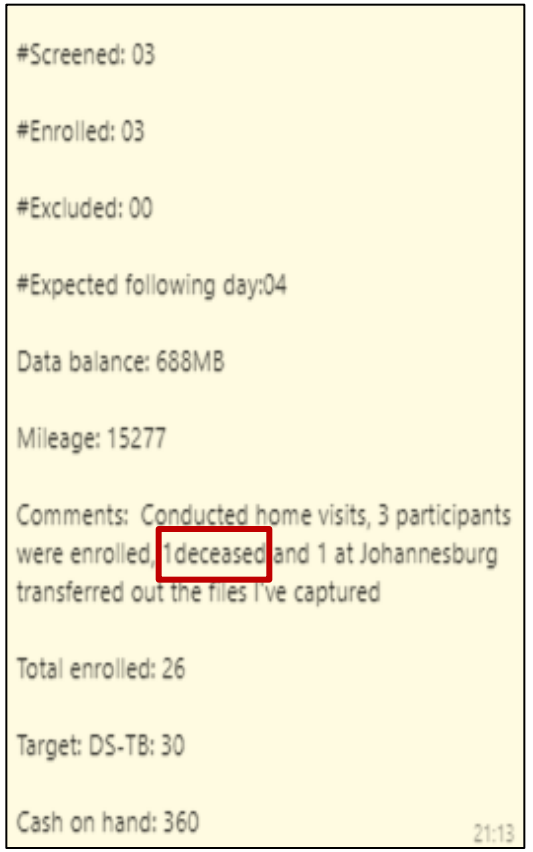
- Accessing patients in most facilities was not easy mainly in rural areas
  - *If difficult for interviewers, it can't be easier for patients*
- Presenting costs alone will not explain the full extent of TB patient experience
- This picture on the right shows our work in Kuruman
  - We drove 45 km from Tshwaragano Hospital to the clinic where the patient was referred
  - Travelled a further 15-20 km to the patient`s home in the village *(patients walk this distance)*
- **Result: Patient not found, must repeat the visit to reach the target**

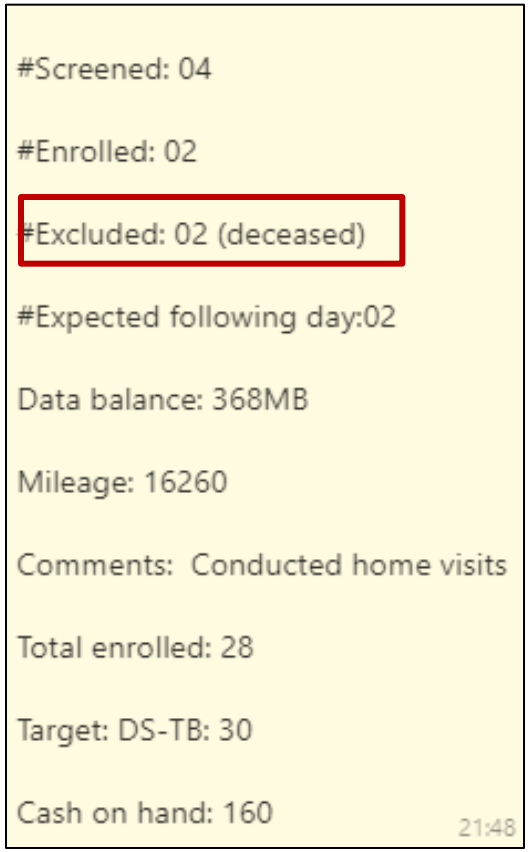
Patients walk miles from the Villages to the Facility... Also travel miles from the Faility to Villages to conduct a Home Visit now on my way to Tsineng Village 🤦‍♀️... I feel for Baby i10😔... Next time Ford Rangers will be Perfect for Village routes

FREQUENT REPORTS OF DECEASED PATIENTS

- Numerous reports of deceased patients
- Screenshots on the right show some daily reports
- In some of these cases, facilities only became aware of these cases after our visits







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RECOMMENDATIONS & IMPLICATIONS

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KEY RECOMMENDATIONS

- Address high catastrophic costs and impoverishing effect of TB (policy interventions and resources)
- Increase coverage of social protection (SASSA and UIF)
- Reduce food insecurity and the cost burden of nutritional supplements
- Reducing facility visits and hours spent seeking or accessing care (decentralized models of care)
- Interventions to mitigate social exclusion (community awareness)
- Strategies to reduce diagnostic delay
- Implementation and Monitoring of interventions

- Multisectoral approach: NDOH, Provinces, DSD, SASSA, Agriculture

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FAQS

- Is it only TB that matters when it comes to patient costs?
- What was the impact of COVID-19 on these results?

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ACKNOWLEDGEMENTS

All facility staff and patients

Provincial Departments of Health

The Technical Advisory Group and Research team

National Department of Health

World Health Organization

The Aurum Institute

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WHAT DO WE NEED TO DO?

Reducing facility visits and hours spent seeking or accessing care

- Reduce the number of facility visits for clinical monitoring
- Strengthen community outreach TB services through WBCOTs
- Strengthen treatment adherence counselling
- Enrolment of TB patients on MMD, CCMDD

Strategies to reduce diagnostic delay

- TB contact tracing, and screening
- Optimising screening and TUTT at facility level
- Targeted community level screening and testing

Address high catastrophic costs and impoverishing effect of TB

- Engage business sector and employers on workplace policies for people with TB
- Strengthening linkages for TB patients and their households to social protection services
- Engagement of relevant government departments, partners and civil society in interventions to address food insecurity – food gardens, income generating projects
- Provision of nutritional supplements for eligible TB patients
- Consider interventions to address poverty as a whole

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CONCLUSION

- This requires a multisectoral approach and initiatives such as the Operation Sukuma Sakhe in KZN have demonstrated that this is possible
- The TB Multisectoral Accountability Framework has been developed to ensure all sectors contribute to the TB response
- Ongoing monitoring of the

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THANK YOU!

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