

THE COST OF BETA THALASSEMIA MAJOR DISEASE FROM PATIENT PERSPECTIVE IN EGYPT

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ABSTRACT

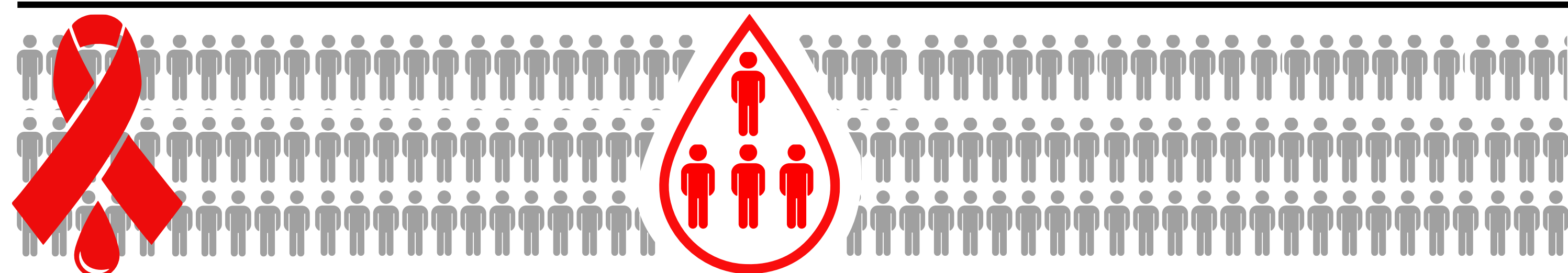
OBJECTIVES: As per the TIF (Thalassemia International Federation) report, Egypt has 10,000 registered thalassemia cases and more than 20,000 non-registered cases where 95% are beta thalassemia major. The Public sector Health Insurance Organization (HIO) covers 7,000 pediatric patients with monthly cost from 1800 EGP to 5000 EGP based on the patient age, however co-payment is still high especially among the adult population. The study aims to calculate the cost of b-thalassemia major among pediatric and adult population in Egypt from patient's perspective.

METHODS: A randomized sample of 35 patients (Adults and caregivers of pediatrics) from both rural and urban areas completed a self-administered survey through the Egyptian Thalassemia Association, stating direct, indirect medical costs they encounter through their disease journey as well as indirect costs (absenteeism), SPSS was used to analyze the data from survey, and then an excel based cost of illness model was then built to project the results to the population.

RESULTS: Total annual cost of B-Thalassemia in Egypt was calculated to EGP 268,737,528 (14.3 M USD) equivalent to EGP 26,874 (1,432 USD) per patient per year, of which direct medical costs contributes with 53% equivalent to EGP 141,302,977 (7.5 M USD) with the highest cost goes to medication and monitoring costs; EGP 64,028,710 (3.4 M USD) and EGP 28,255,806 (1.5 M USD) respectively. Direct non-medical costs were calculated to be 4% equivalent to EGP 11,602,968 (618,360 USD). Indirect cost was 43% equivalent to EGP 115,831,583 (6.1 M USD) with absenteeism of adult patients and caregivers of pediatrics equivalent to EGP 67,060,390 (3.6 M USD) and EGP 48,771,193 (2.6 M USD) respectively.

CONCLUSION: Even with the insurance coverage of the public sector, Thalassemia patients still suffer a high financial burden given the average annual wages in Egypt, especially the adult patients.

INTRODUCTION



4.4 in 10,000 Male Births

Is an estimated worldwide incidence of hemophilia per year¹

There are 2 types of Thalassemia;



Alpha thalassemia

Beta thalassemia

Both of them have same subtypes which are Thalassemia Major and Thalassemia Minor, where Thalassemia Major is the subtype with the more severe symptoms, requiring the inheritance of the gene defect from parents. Egypt is one of the heavily affected countries with **1,000** children out of **1.5 million** live births suffering from thalassemia each year. The lives of thalassemia patients and their caregivers are way harder in terms of day to day activities, education, marriage and work.

OBJECTIVES



As per the Thalassemia International Federation report, Egypt has **10,000 registered thalassemia cases** and more than **20,000 non-registered cases** where **95%** are beta thalassemia major.

The Public sector Health Insurance Organization (HIO) covers 7,000 pediatric patients with monthly cost from 1800 EGP to 5000 EGP based on the patient age, however co-payment is still high especially among the adult population. The study aims to calculate the cost of b-thalassemia major among pediatric and adult population in Egypt from patient's perspective.

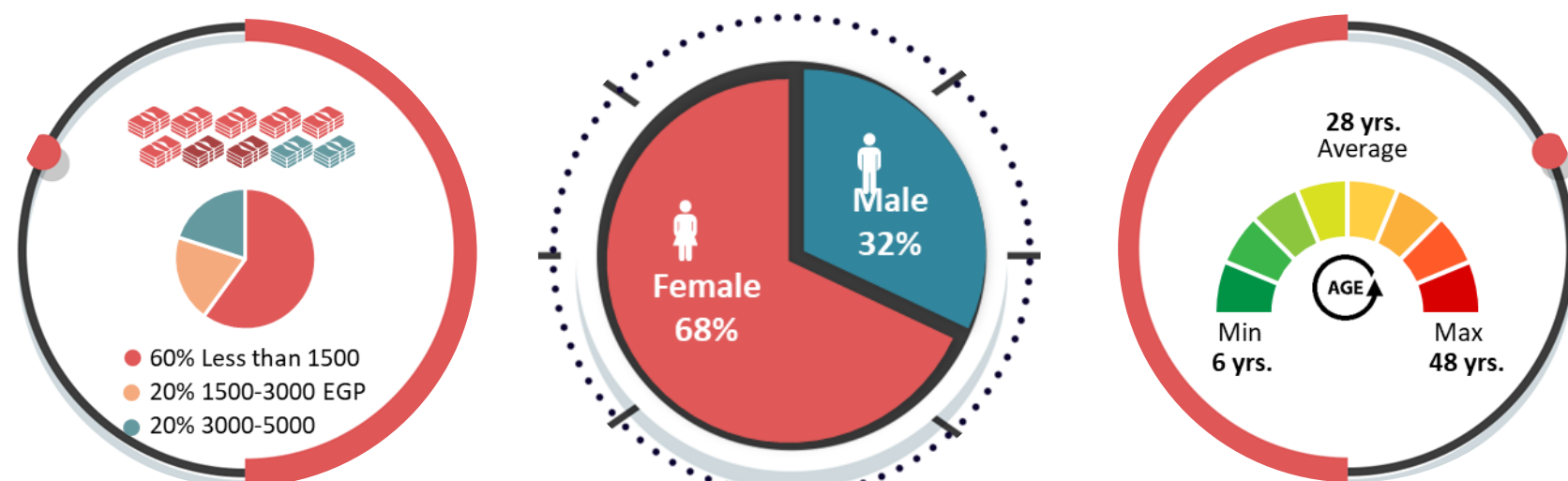
METHODOLOGY



A randomized sample of 35 patients
(Adults and caregivers of pediatrics)

from both rural and urban areas completed a CATI survey through the Egyptian Thalassemia Patients Friends Foundation, stating direct medical, and direct non medical costs they encounter through their disease journey as well as indirect costs (absenteeism), SPSS was used to analyze the data from survey, and then an excel based cost of illness (COI) model was then built to project the results to the population. The COI model was built bottom-up from patients perspective with segmentation as pediatric and adult patients, as well as gender.

The Average Days of treatment initiation after diagnosis with Thalassemia is max **7 days** and min **1 Day**



RESULTS

Total cost of B-Thalassemia Per Annum



268,737,528 EGP (14.3 M USD)



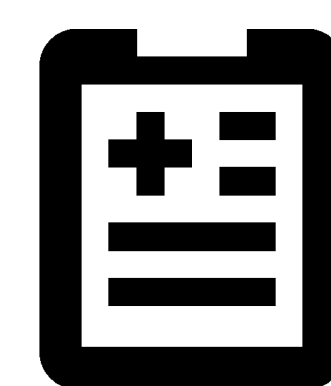
26,874 EGP (1,432 USD)

In average per patient per year

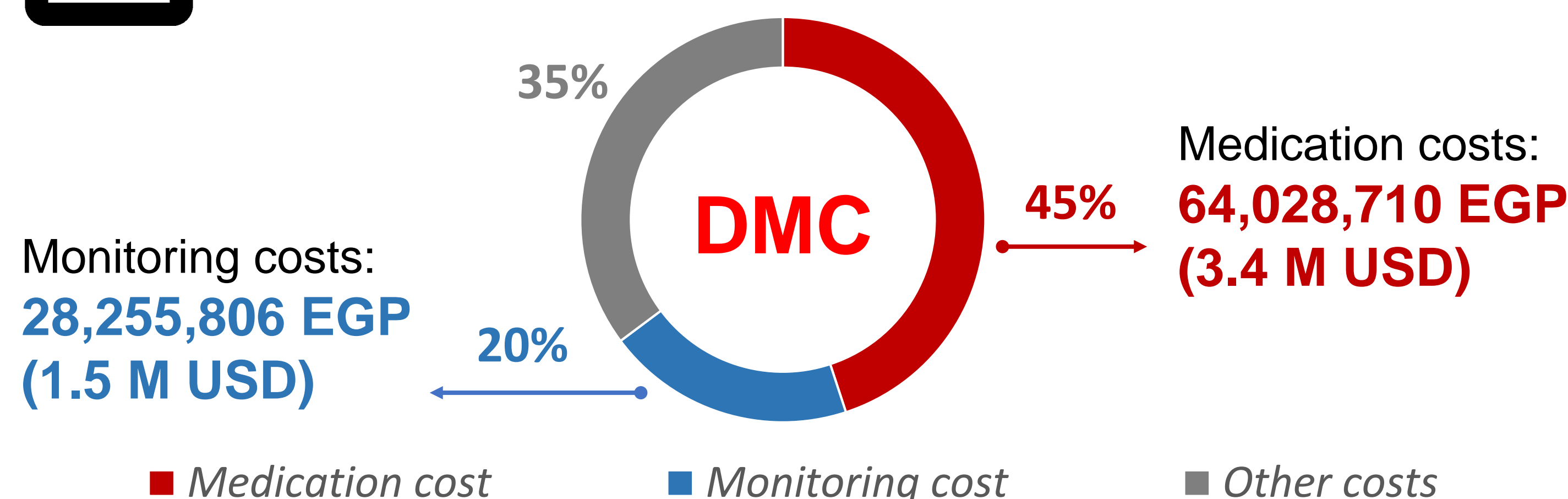
Direct Vs Indirect Costs



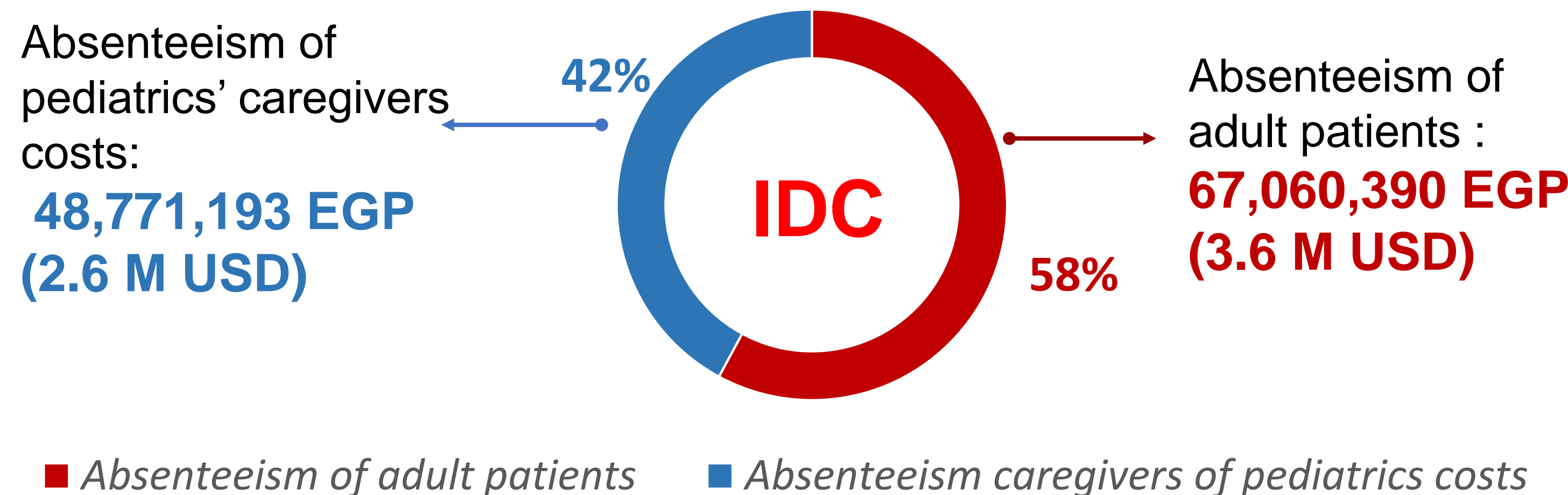
■ Direct Medical Cost ■ Indirect Cost ■ Direct non-medical costs



Direct medical costs contributes with **53%**, equivalent to **141,302,977 EGP (7.5 M USD)**, Highest cost goes to;



Indirect cost was **43%** equivalent to **115,831,583 EGP (6.1 M USD)**, and it goes to;



CONCLUSION

Even with the insurance coverage of the public sector, Thalassemia patients still suffer a high financial burden given the average annual wages in Egypt, especially the adult patients.