

The Disease Burden of Systemic Sclerosis in the Russian Federation

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INTRODUCTION

Systemic sclerosis (SSc) is a severe orphan connective tissue disease and a cause of multiple life-threatening comorbid conditions, which is why it is associated with high mortality rates. The treatment of SSc and its complications imposes a significant financial burden on the healthcare system. Moreover, the progressive nature of the disease substantially impacts patients' health and professional lives, leading to early disability, loss of productivity, and job loss.

OBJECTIVE

To assess the disease burden of SSc from the Russian government and societal perspectives by evaluating both direct costs (treatment of the disease and its complications) and indirect costs (economic losses due to disability and premature mortality).

METHODS

Based on registry data and treatment patterns in the Russian Federation, the number of patients with SSc and the prevalence of the most common complications were assessed. Subsequently, an evaluation of direct medical costs was conducted based on the frequency of prescribing specific therapies for both the primary disease and associated complications.

The calculation of indirect costs took into account economic losses due to premature mortality, reduced productivity due to disease progression, as well as premature job loss. These were assessed using the "human capital" approach over a 1-year horizon.

DATA SOURCES

Published and grey literature, Russian clinical guidelines, Russian diagnosis-related group (DRG) grouping, Russian registry of maximum selling drug prices, expert opinion.

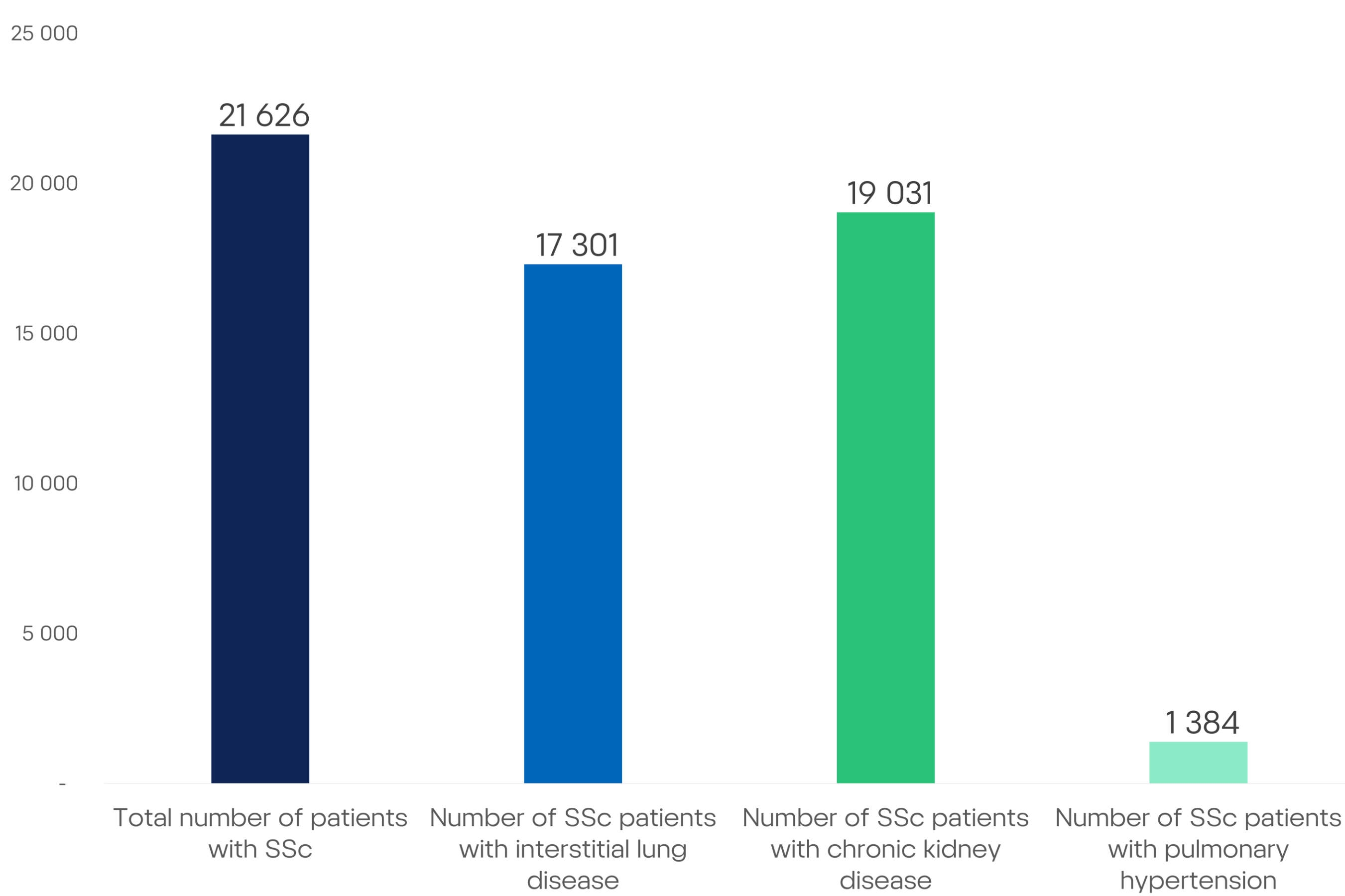


Figure 1. Structure of patient population with SSc in Russia (2025)

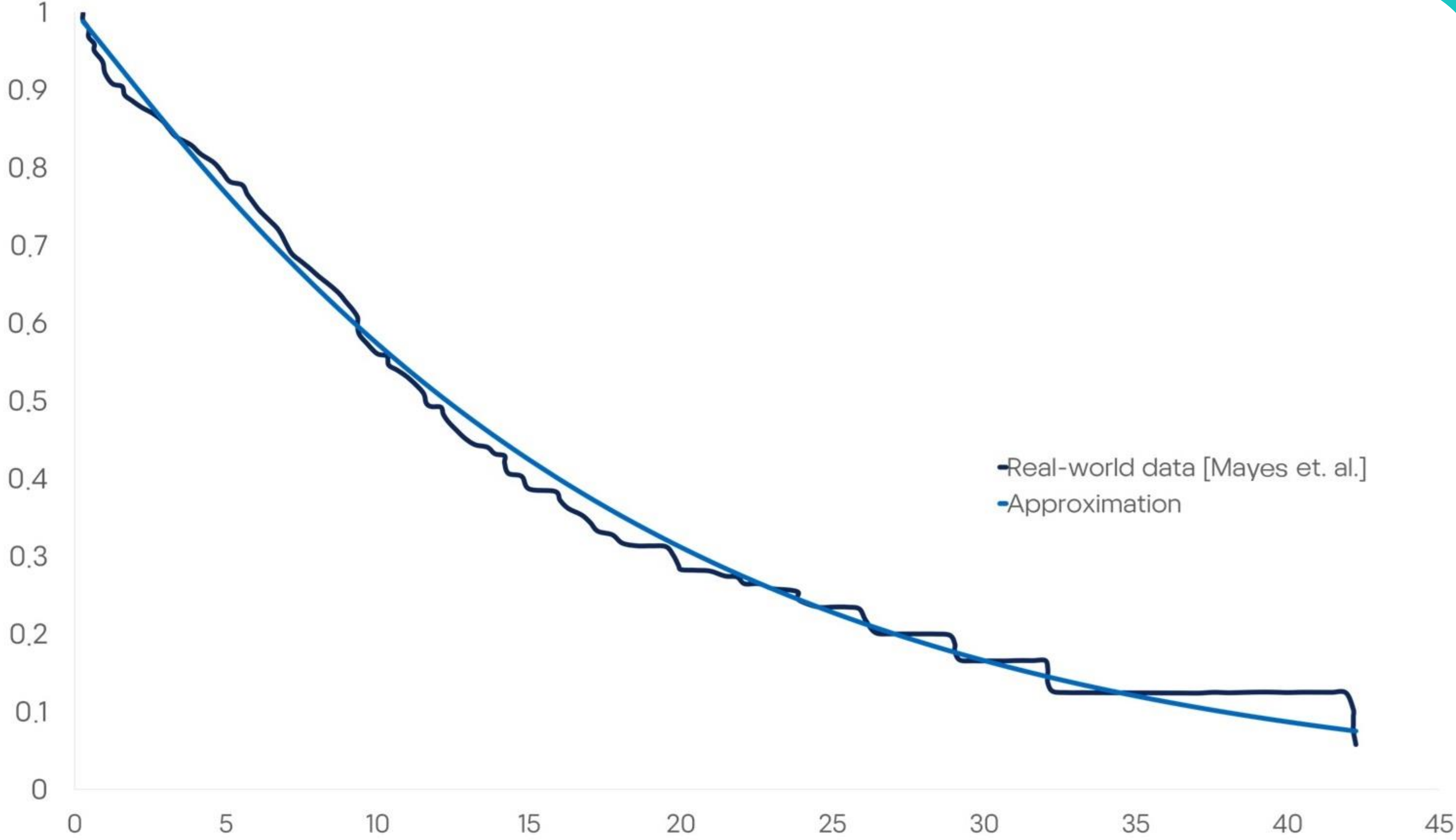


Figure 2. Kaplan-Meier survival curves for SSc patients

	Mean annual costs per patient, \$	Incidence of complications, %	Total annual costs, \$
SSc main treatment costs	376		7 944 160
Total complications treatment	3 915		82 681 711
Interstitial fibrosis	2 842	80	48 015 675
Pulmonary arterial hypertension	9 407	6.4	12 716 113
Chronic kidney disease	1 181	88	21 949 923
Total direct medical costs	4 291		90 625 871

Table 1. Direct costs of SSc

Ultimately, 2/3 of SSc annual economic burden in Russia was attributed to indirect costs (fig. 3). High rates of premature death (more than 1,000 SSc patients per year) and disability progression led to annual economic losses of 164.6 million USD for Russian SSc patient cohort along with 24.8 million USD loss accounting for reduced labor force participation and productivity (fig.4).

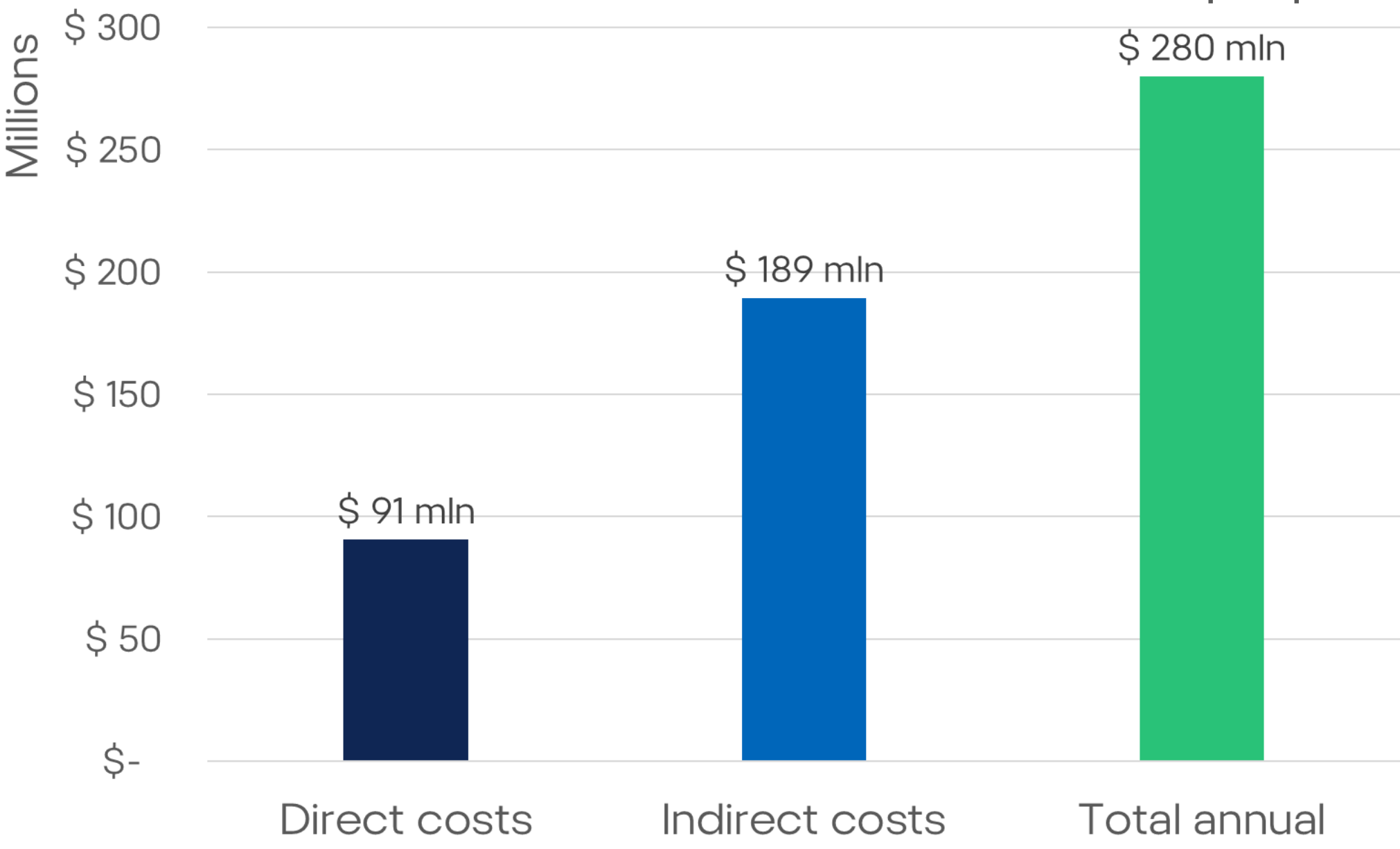


Figure 3. Annual SSc costs in Russian Federation

RESULTS

We used Russian government statistics on SSc patients and complications (fig.1). To estimate mortality we reconstructed individual patient data from registry and approximated them with a parametric survival function for SSc population (fig.2). Total direct medical costs for the treatment of 21,626 Russian SSc patients amounted to 90.6 million USD per year (Table 1). The cost of illness analysis showed that the treatment of complications accounted for the majority of direct medical costs, while the treatment of the primary disease represents only 8.7% of the total due to limited number of treatment options available and lack of their effectiveness. Interstitial fibrosis therapy made the largest contribution to direct costs, primarily due to the high prevalence of the disease and the presence of only two expensive drugs in the clinical guidelines. The annual mean medical costs per patient with SSc and interstitial fibrosis was 2,841.76 USD. In contract, a large number of diverse drugs to treat chronic kidney disease complications and a small number of patients requiring dialysis led to relatively low costs per patient: 1,018.84 USD respectively.

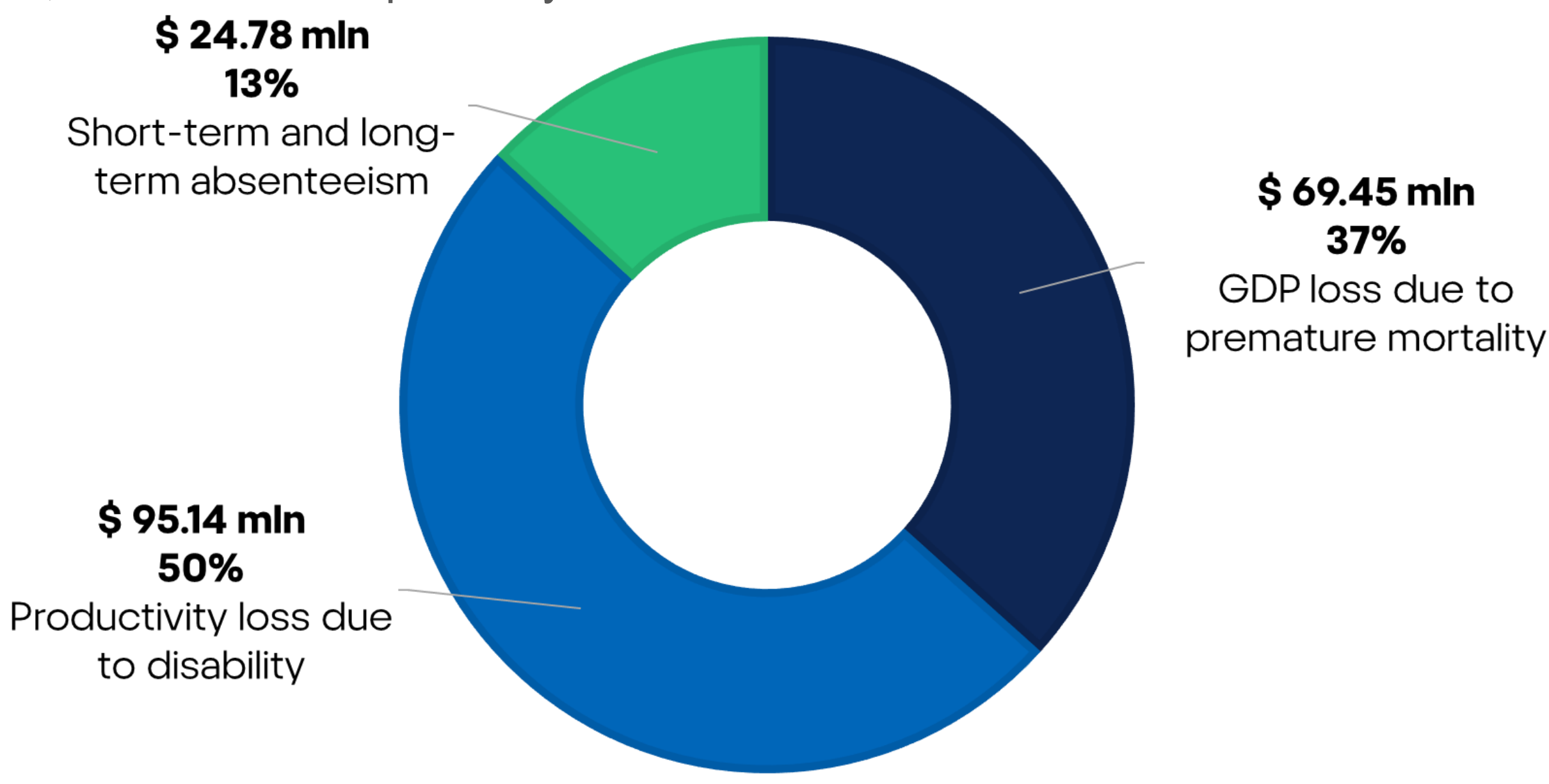


Figure 4. Annual indirect costs of SSc

CONCLUSIONS

Lack of therapies for SSc has forced patients to rely on largely ineffective treatments (nearly all drugs for the primary disease were used off-label). This contributes to the development of numerous life-threatening complications, which consume most direct medical costs and ultimately result in early death. Simultaneously, patients experienced significant decline in work productivity, job loss, unemployment, and substantial economic losses.

REFERENCES



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