

# Thalassaemia in Pakistan

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**In the name of Allah, the most  
gracious, the most merciful.**

# Outline

- Pakistan – a glimpse
- Healthcare Systems in Pakistan
- Where do thalassaemics get their care?
- Prevention Programs in different provinces
- Legislations?









**Afghanistan**

**JAMMU AND  
KASHMIR**

**HIMACHAL  
PRADESH**

**Pakistan**

**PUNJAB**

**UTTARAKH**

**HARYANA**

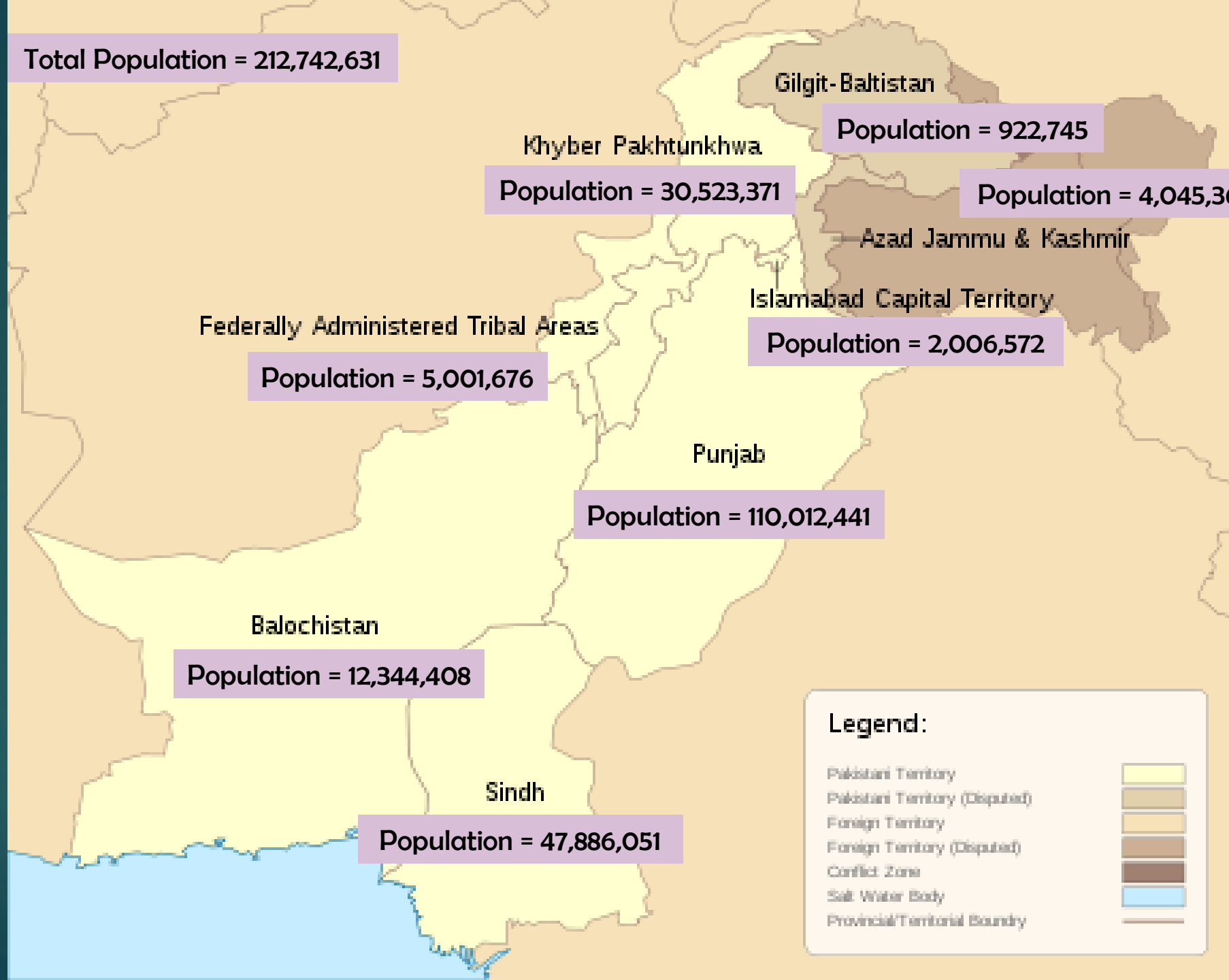
**UTT  
PRAD**

**RAJASTHAN**

**GUJARAT**

**Ind**

Total Population = 212,742,631



**Legend:**

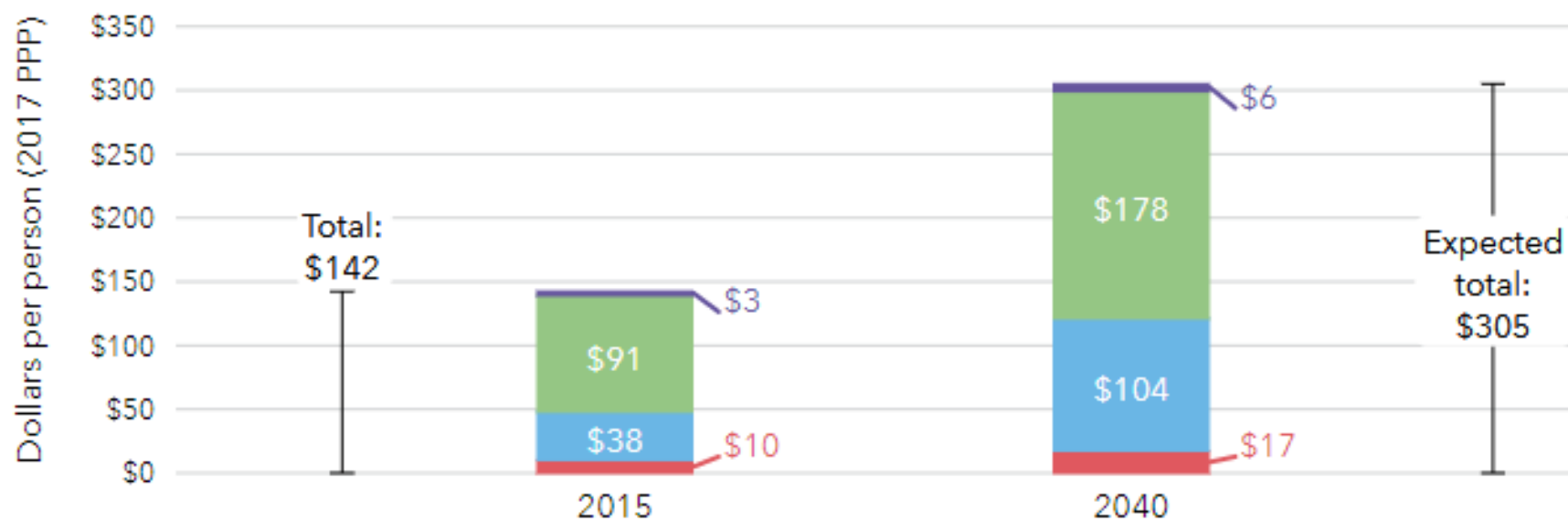
- Pakistani Territory
- Pakistani Territory (Disputed)
- Foreign Territory
- Foreign Territory (Disputed)
- Conflict Zone
- Salt Water Body
- Provincial/Territorial Boundry

# Healthcare systems in Pakistan

- ▶ Ranks 147 on the Human Development Index in 2016
- ▶ <1% of GNP spent on health
- ▶ Devolved to 8 federal units by 18<sup>th</sup> amendment in 2010
- ▶ Strategic planning is also a provincial responsibility
- ▶ Private sector widely used (70%) and government sector (30%)

## How much is spent on health -- now, and in the future -- and from which sources?

- Prepaid private spending
- Out-of-pocket spending
- Government health spending
- Development assistance for health



Source: Financing Global Health Database 2017

PPP = purchasing power parity

"Expected" is the future growth trajectory based on past growth.



# Disease Burden

- A population of over 200 million
- Calculated estimates with a gene frequency of 5 - 8% means approx. 10 million thalassaemia carriers across the country
- Calculated estimate of 7000 new births of B-thalassaemia Major each year
- Calculated estimate of over 100,000 Thalassaemia major patients across the country

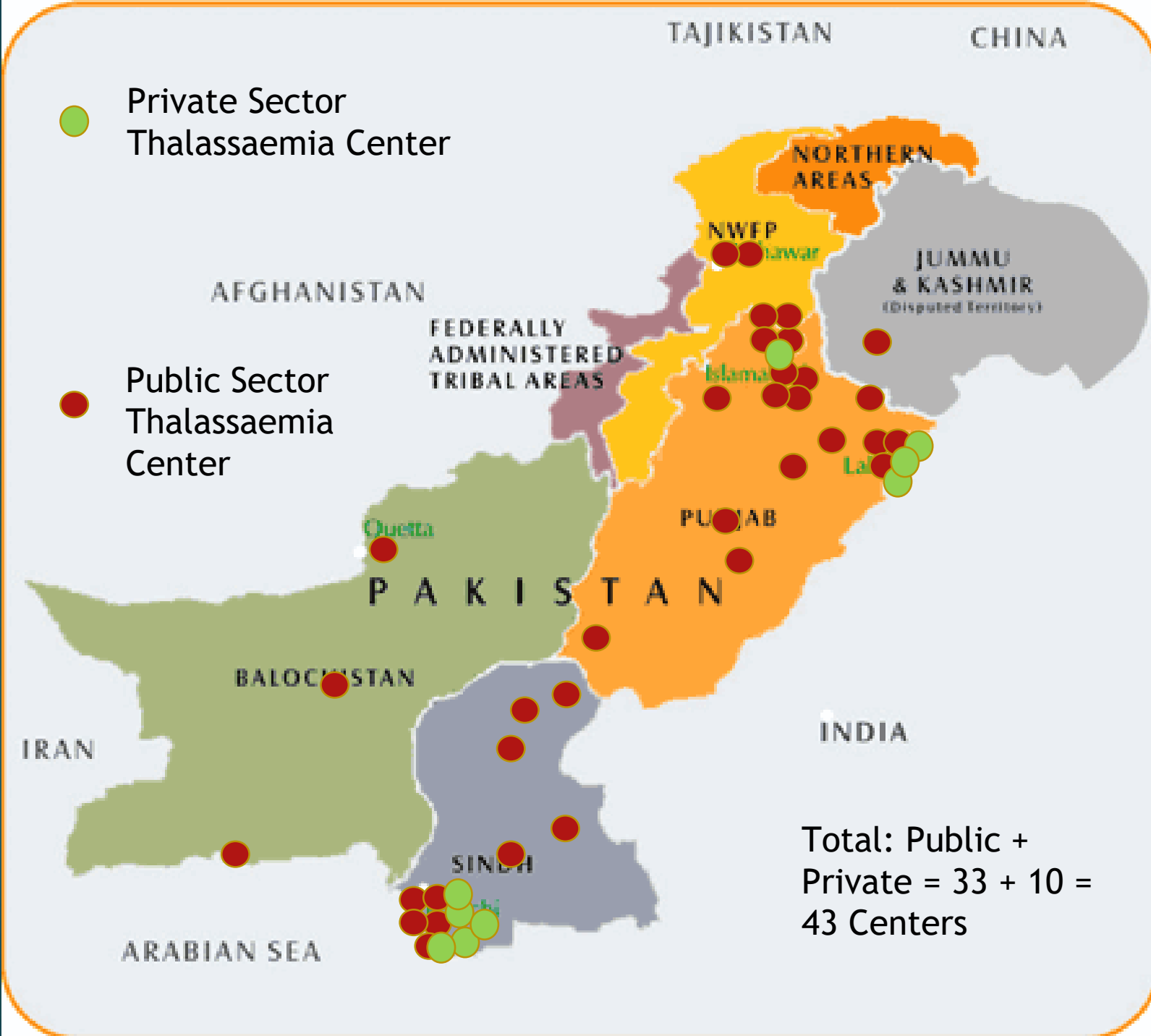


# Thalassaemia care in Pakistan

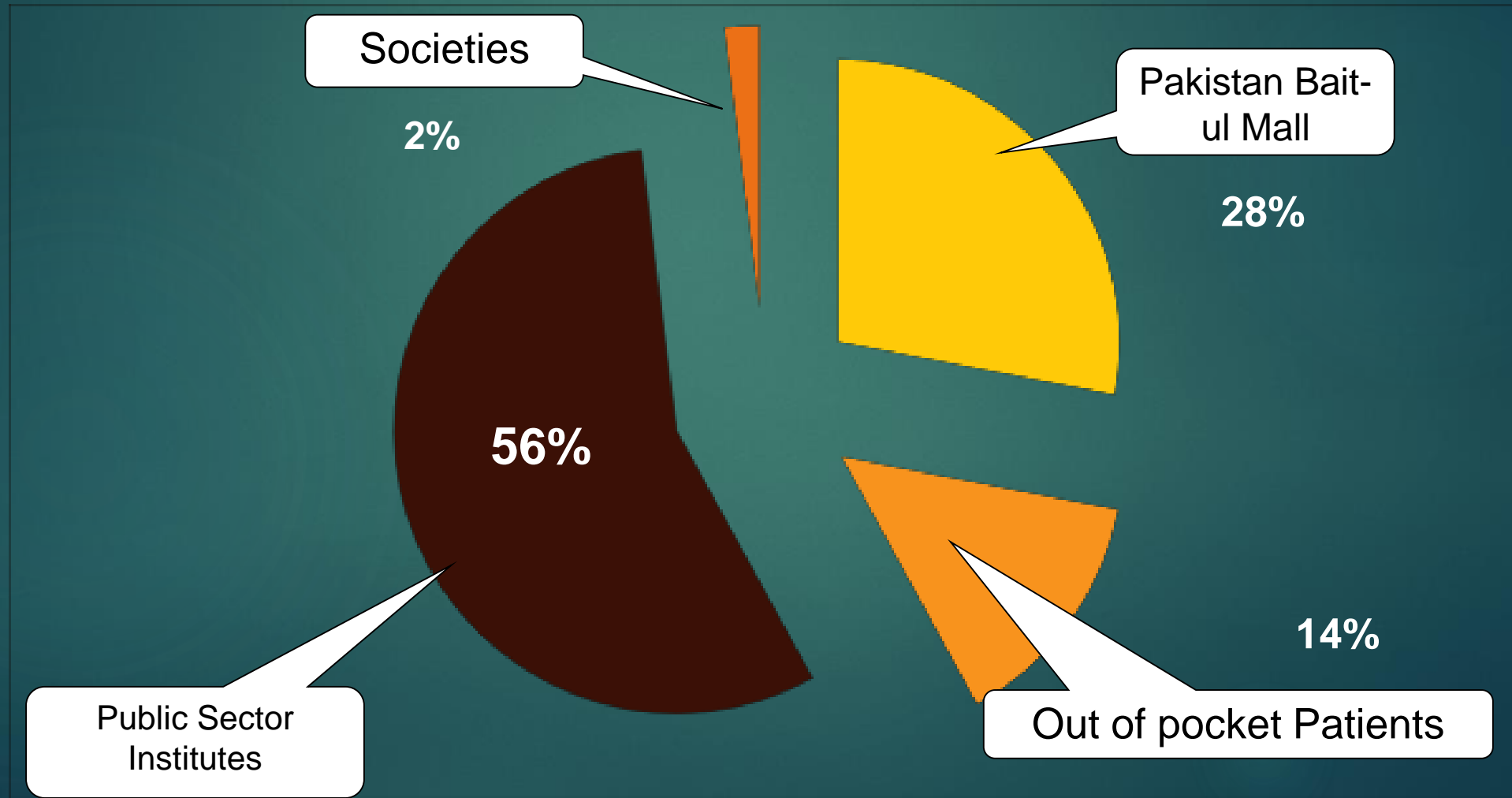
# Where do patients get their care in Pakistan?

- Traditionally NGO's - 43
- Hospitals - Private / Public = 10 / 33 = 43
- General practitioners
- Faith healers
- Homeopathic doctors





# Who pays for the Medication??



# How is medicine procured?





# Prevention strategies in Pakistan

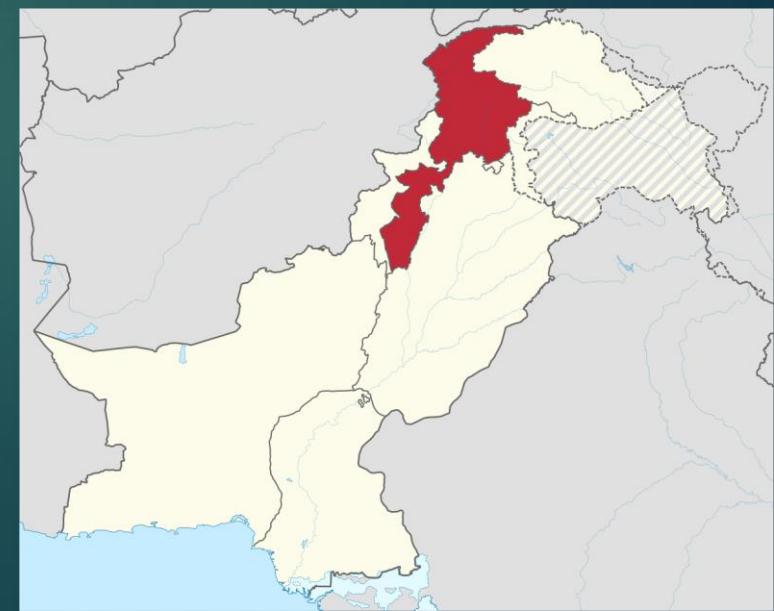
- ▶ Awareness seminars
- ▶ Carrier screening –
  - ▶ Extended family,
  - ▶ Mandatory
  - ▶ Selective
- ▶ Prenatal diagnosis – Termination of Pregnancy

# Prevention

- Prevention Programmes are running in 3 provinces.
  - ▶ KP – Thalassaemia Prevention Programme
  - ▶ Sindh Thalassaemia Prevention Programme
  - ▶ Punjab Thalassaemia Prevention Programme

# Khyber Pakhtunkhwa

- ▶ Initially started a Thalassaemia Prevention programme in 2005.
- ▶ Was involved in “**War on Terror**”, thus could not really evolve.
- ▶ Restarted in 2015 with an aim to emulate the model of Punjab.





# Sindh Thalassaemia Prevention Programme

- ▶ Currently only involved in legislation in the province.
- ▶ Most prevention efforts are head by NGO's and are limited.



# Punjab Thalassaemia Prevention Programme

- ▶ Most robust thalassaemia prevention programme in the country.
- ▶ Based on extended family screening of index cases as well as voluntary screening
- ▶ Throughout all 36 districts of the province and possibly the largest prevention programme of its sort catering to a population of 110 million people.





## Punjab Thalassaemia Prevention Programme

Government of The Punjab

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# Legislations ?

Mandatory screening of all couples prior to marriage ?

Screening of all male members of the population and if a carrier then mandatory screening of the spouse

Concerns:

- ▶ Lack of healthcare facilities which can screen
- ▶ Individual rights infringement and stigmatization

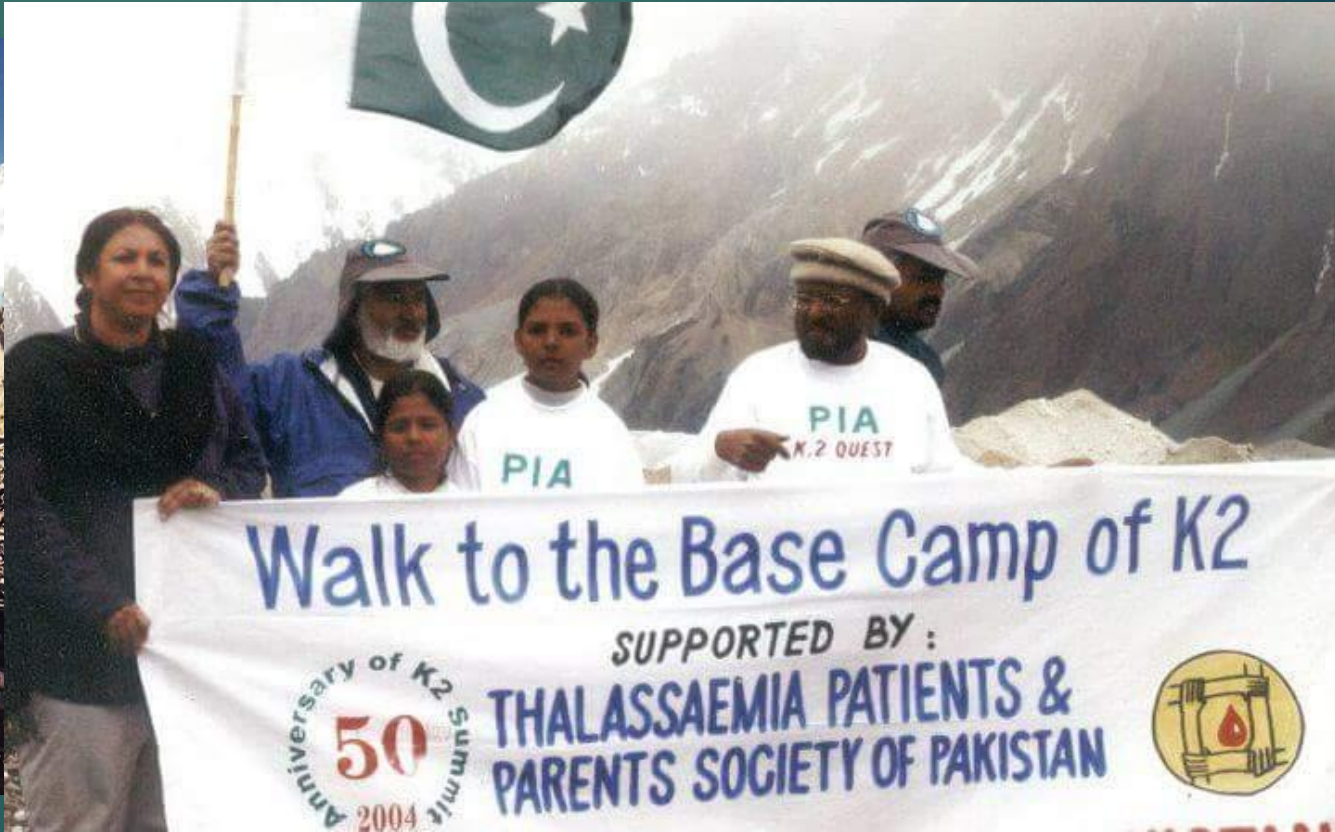


# Pre-marriage blood screening in Punjab

The Punjab Thalassaemia Prevention and Treatment Programme (PTPP) has finalised a draft bill to legislate compulsory pre-marriage blood screening of couples.

**DAWN**

<https://www.dawn.com/news/1360317/draft-bill-finalised-for-pre-marriage-thalassaemia-test>









# Batool with me at Amina Bashir Memorial Trust, Misri Shah, Lahore

