

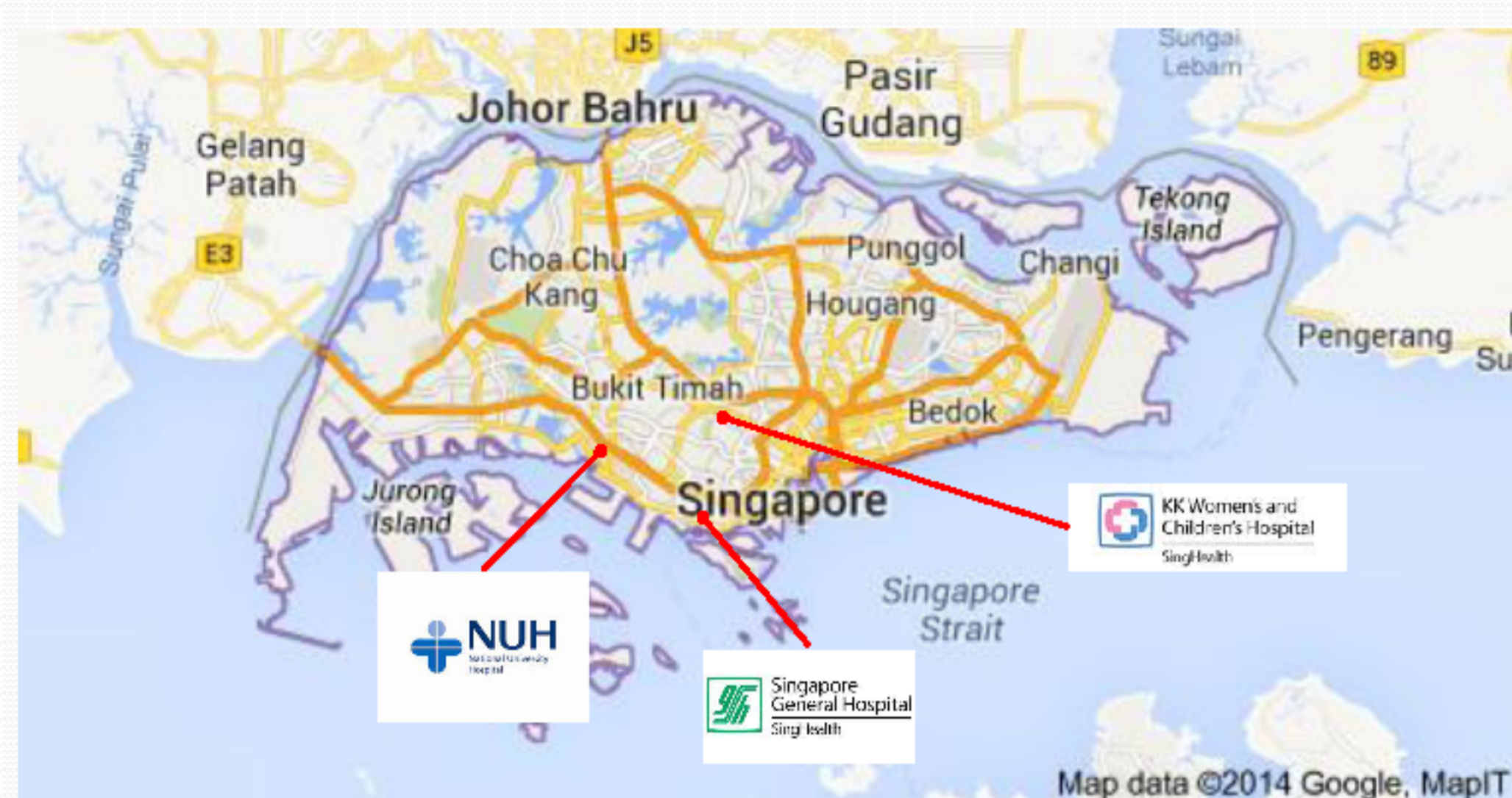
A Comprehensive Review of Current Haemophilia Care and Outcomes in Singapore

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Introduction

As a small island nation, haemophilia care in Singapore is delivered by a modern and easily accessible state-funded health care system through a network of 3 tertiary care hospitals. Our model of health care ensures the provision of quality and affordable basic medical services for all and taps on state-funding, medical insurance, retirement savings fund and co-payment by patients for the provision of health care services and consumables. This hybrid model assures that all our haemophiliacs receive on-demand therapy as standard of care and have the potential to receive prophylactic treatment if indicated.

We report data from our National Haemophilia Registry and surveyed a representative section of our patients to determine how they have fared with this model of health care.



Haemophilia care institutions and their location in Singapore

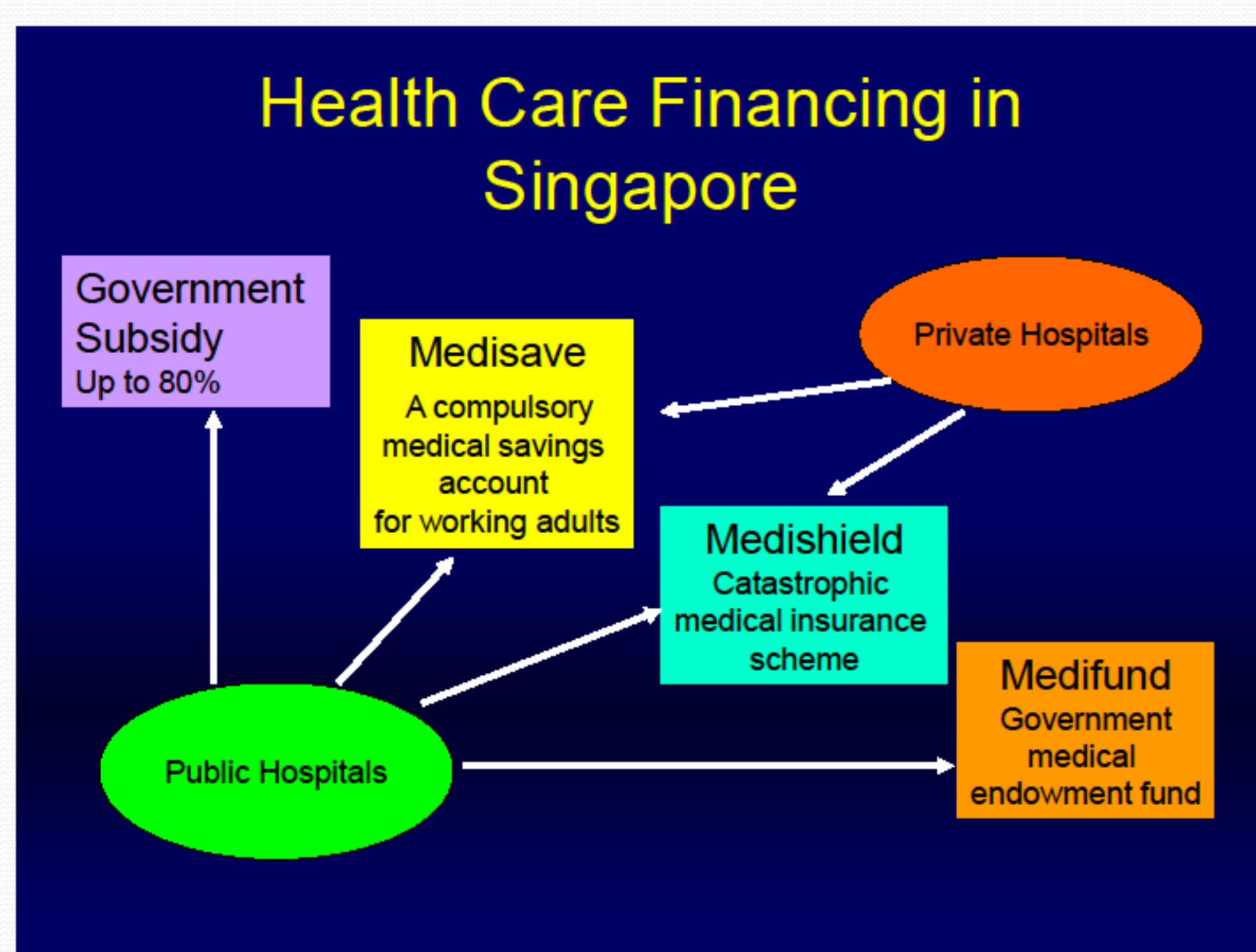
Materials and Methods

This study was conducted in 2013. Data from the Singapore National Haemophilia Registry provided baseline demographic information on people living with haemophilia A and B. Population and health care statistics on Singapore were obtained from the Department of Statistics, Singapore. All haemophiliacs listed in the Registry were invited to participate in this study at the time of their scheduled annual visits to our haemophilia clinics. A set of questionnaires that explores further details of their treatment, complications and socio-economic data was provided to consenting participants for completion during the study visit. In addition, all participants were assessed by a site investigator for the status of their joints using the Haemophilia Joint Health Scores (HJHS).

This study was approved by the Institutional Review Boards of all 3 participating institutions. Study participants did not receive any compensation.

Singapore Fast Facts (2013)

Land Area: 716 square kilometers
 Total Population: 5,399,200
 Singapore Residents: 3,844,800
 Population Density: 7,540 per square km



Results

Among a total of 195 haemophilia A and 40 haemophilia B individuals, a total of 95 haemophilia A and 16 haemophilia B individuals consented to participating in this study and provided further information as per study protocol. The baseline demographic information of all haemophiliacs and study characteristics of participants are illustrated below.

Table 1. Severity, age distributions and inhibitor status of haemophilia A and B patients in Singapore. (Data from Singapore National Haemophilia Registry)

	Haemophilia A			Total
	Mild	Moderate	Severe	
Severity	67	64	64	195
Age distribution				
0-10	3	6	11	20
11-20	4	12	14	30
21-30	15	15	3	33
31-40	12	10	12	34
41-50	12	8	9	29
51-60	9	12	11	32
Above 60	12	1	4	17
Ethnicity				
Chinese	59	45	47	151
Malays	3	15	8	26
Indians	5	3	7	15
Sikh	0	0	2	2
Others	0	1	0	1
Inhibitors				
High responders	0	5	6	11
Low responders	1	1	3	5
Transient	1	9	9	19
	Haemophilia B			Total
	Mild	Moderate	Severe	
Severity	16	14	10	40
Age distribution				
0-10	0	3	5	8
11-20	0	2	3	5
21-30	5	4	1	10
31-40	8	2	0	10
41-50	0	2	0	2
51-60	3	1	1	5
Above 60	0	0	0	0
Ethnicity				
Chinese	13	11	9	33
Malays	2	3	0	5
Indians	0	0	1	1
Others	1	0	0	1
Inhibitors	0	0	1	1

Table 2. Socio-economic status of 95 haemophilia A and 16 haemophilia B individuals

	Haemophilia A			Haemophilia B
	Mild	Moderate	Severe	
Minors (<18)	0	10	22	6
Adults	13	26	22	10
Marital Status (adults only)				
Single	6	11	12	7
Married	7	13	9	3
Divorced/separated	0	1	1	0
Living with partner	0	0	0	0
Widowed	0	0	0	0
Unknown	0	1	0	0
Occupation				
Pre-school	0	3	6	4
Student	2	7	19	3
Employed, part-time	1	4	1	0
Employed, full-time	8	12	10	6
Unemployed	1	8	4	2
Permanently disabled	0	0	1	0
Retired	1	2	1	0
Unknown	0	0	2	1
Annual household income (SGD)				
<20,000	2	10	8	2
20,000 - 39,999	1	13	9	2
40,000 - 59,999	1	1	3	5
60,000 - 79,999	1	1	6	1
80,000 - 99,999	3	5	4	0
>100,000	1	2	0	1
Not available	4	4	14	5
Health insurance*				
None	3	25	31	11
Public	6	7	7	1
Private	6	5	4	5
On medical social services assistance	0	15	21	7

Table 3. Bleeding manifestations and complications among haemophilia patients

	Haemophilia A			Haemophilia B
	Mild	Moderate	Severe	
No bleeding	0	1	0	0
Age at first bleed (range) years	8 months to 30 years	At birth to 24 years	3 days to 13 years	1 day to 29 years
Site of first bleeding				
Intracranial	0	2	3	4
Oral Mucosa	3	8	2	2
Circumcision	2	0	0	1
Joint	3	2	9	1
Intramuscular injection	0	0	2	0
Others	5	21	18	5
Unknown	0	4	10	3
Number of bleeding sites				
1	8	9	10	5
2	4	2	15	5
3	0	14	10	3
>3	1	10	8	1
Average number of bleeds per year (range)	0.5 (0-3)	20.5 (0-52)	21.5 (1-104)	13.0 (0-48)
Number of target joints				
1	0	9	14	5
2	0	4	7	1
3	0	2	5	0
>3	0	6	4	0
Intracranial bleeds and other life-threatening bleeds	1	15	7	5

Results

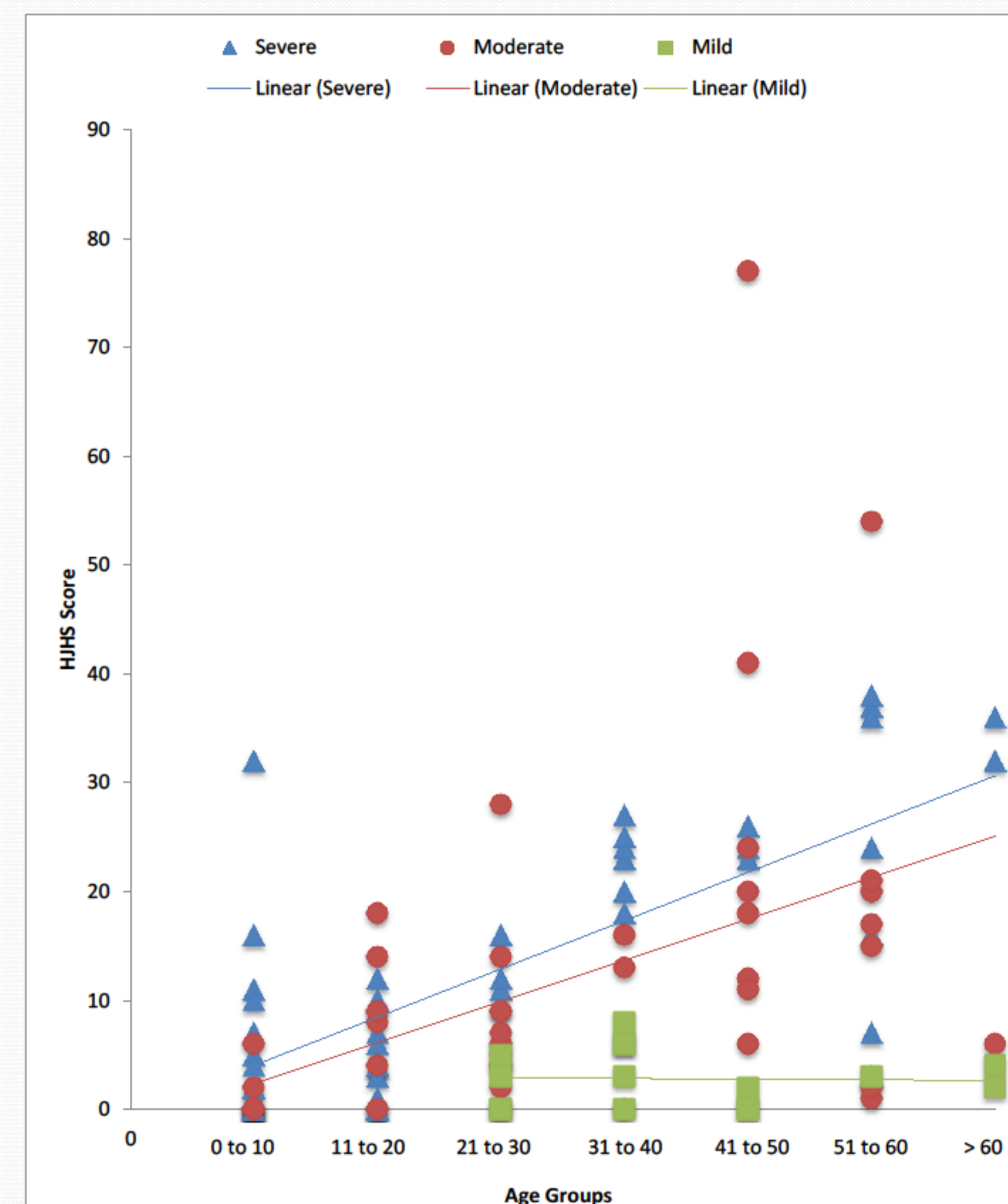
Table 4. Current treatment among 93 haemophilia A and 16 haemophilia B individuals in Singapore

	Haemophilia A			Haemophilia B
	Mild	Moderate	Severe	
Mode of factor replacement				
On demand	13	27	31	12
Primary prophylaxis	0	0	2	2
Secondary or tertiary prophylaxis	0	11	11	1
Type of factor concentrates				
Plasma-derived	9	33	39	15
Recombinant	4	3	6#	1
Home treatment	1	22	30	9
Person administering home treatment				
Self	1	20	22	5
Parents	0	3	10	6
Relatives	0	0	1	0
Others	0	1	1	1
Treatment for target joints				
Synovectomy	0	10	12	1
Radionuclide	0	10	11	0
Arthroscopic	0	0	2	0
Open	0	0	0	0
Joint replacement	0	1	1	0
Arthrodesis	0	0	0	0

Table 5. Complications associated with factor replacement, bleeding and other co-morbidities

	Haemophilia A			Haemophilia B
	Mild	Moderate	Severe	
Blood product-borne infections				
Hepatitis C	4	14	14	3
HIV	0	0	0	0
Epilepsy	0	5	2	1
Cancer	1	1	0	0
Hypertension	1	7	5	2
Diabetes	1	1	3	0
Cardiovascular disease	0	1	2	0

Figure 1. Distribution of Haemophilia Joint Health Score (HJHS) by age group and severity of disease



Conclusions

The prevalence of haemophilia is consistent across all age groups with a racial distribution that is proportional to the ethnic composition of Singapore. On-demand therapy has been the mainstay of factor replacement therapy for our adult patients. Increasingly, regular primary or secondary prophylaxis therapy is being employed to reduce bleeding events and complications among our people living with haemophilia. Most of our paediatric haemophiliacs are now on regular prophylaxis therapy. While most consumed clotting factors are plasma-derived, an increasing number of paediatric patients are now using recombinant clotting factor products as we seek to reduce the price difference between the 2 lines of products. The Haemophilia Joint Health Scores for our patients corresponded to the age of individuals and severity of their haemophilia.

Haemophilia care in Singapore will continue to focus on reducing early and late complications of bleeding events by providing greater access to appropriate factor replacement and optimising the physical status of our people.

