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### Can inequity in healthcare be bridged in LMICs – Multicentre experience from thalassemia day care centres in India

Lalith Parmar<sup>a,\*</sup>, Amit Sedai<sup>a,b</sup>, Kumari Ankita<sup>a</sup>, Rakesh Dhanya<sup>a</sup>, Rajat Kumar Agarwal<sup>a,b</sup>, Sunil Dhimal<sup>b</sup>, Reshma Shriniwas<sup>c</sup>, Hemanth V. Iyer<sup>c</sup>, Ashwini Gowda<sup>c</sup>, Pooja Gujjal<sup>d</sup>, H. Pushpa<sup>a,d</sup>, Suman Jain<sup>e</sup>, Saroja Kondaveeti<sup>e</sup>, J. Dasaratha Ramaiah<sup>f</sup>, Raviteja<sup>f</sup>, Sujata Jali<sup>g</sup>, Neelavva Rayappa Tallur<sup>g</sup>, Stalin Ramprakash<sup>h</sup>, Lawrence Faulkner<sup>a,h,i</sup>

<sup>a</sup> Sankalp India Foundation, Bangalore, India

<sup>b</sup> Jagriti Innovations, Bangalore, India

<sup>c</sup> Project Samraksha, Rashtrorathana Parishat, Bangalore, India

<sup>d</sup> Indira Gandhi Institute of Child Health, Bangalore, India

<sup>e</sup> Thalassemia and Sickle Cell Society, Hyderabad, India

<sup>f</sup> Rural Development Trust Hospital, Ananthpur, India

<sup>g</sup> Jawaharlal Nehru Medical College, Belgaum, India

<sup>h</sup> Sankalp-People Tree Centre for Pediatric BMT, Bangalore, India

<sup>i</sup> Cure2Children Foundation, Florence, Italy

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#### 1. Background

The WHO defines equity as the absence of avoidable or remediable differences among groups of people, whether those groups are defined socially, economically, demographically, or geographically [1]. Reducing preventable and unjust health inequities has been gaining increasing importance globally [2–4].

Even in the most well-funded health setups of the developed world, the problem of inequity continues to persist [5–7]. Similarly,

it has been shown that increasing health spending may not necessarily translate into reducing inequity and may even selectively benefit the more advantaged groups [8–11]. The need for greater focus on reducing disparity in healthcare delivery even in the countries with low mortality has been recognised [8]. Inequity is a problem separate from the availability of resources and needs specific focus even in developing countries [12].

There are mixed reports on the effectiveness of measures taken to tackle inequity both in terms of cost and success in LMICs [13,14]. Advances in information and communication technology have greatly increased the potential to effectively measure disparities in medical care access [15]. If monitoring systems are employed in healthcare report performance data and presented in relation to factors affecting health equity, it creates the evidence base for equity-oriented interventions [16].

Beside global studies [3], experiences from Africa [10], South America [17] and South East Asian Region [18] all agree that poverty, education, sex inequalities, place of stay and other social determinants of health are strongly linked to inequities. In India, health equity data at the primary healthcare level is available: The National Family Health Survey [19] and National Sample Survey Office (NSSO) [20] routinely measure health equity in India. Key factors leading to inequity in India are economic status, geography, sex and education [21].

As significant advances are being made in tackling communicable diseases, non-communicable diseases (NCDs) are becoming the largest contributors to preventable mortality and morbidity. Severe thalassemia syndromes (ST) are the most prevalent life-threatening non-communicable disorder of childhood [22] in

\* Corresponding author. #18/8,1st floor, 3rd Cross, Nagappa Street, Malleshwaram, Bangalore, 560003, India

E-mail address: [lalith@sankalpindia.net](mailto:lalith@sankalpindia.net) (L. Parmar).

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### Abbreviations

ST	Severe Thalassemia
PTH	Pre-transfusion Hemoglobin
BPL	Below poverty line
APL	Above poverty line
IGI	Indira Gandhi Institute of Child Health
SAM	Project Samraksha
TSC	Thalassemia and Sickle Cell Society
RDT	Rural Development Trust
KLE	Jai Shivshakti Centre for Thalassemia (Jawaharlal Nehru Medical College)
IQR	Inter-quartile range

South-East Asia and a major financial burden [23–25]. Children suffering from severe thalassemia syndromes (ST) require periodic blood transfusions for life. Beside transfusions, the management of ST also involves control of iron overload, replacement of nutrients, regular monitoring, prevention and management of several complications etc. As a result of high costs and poor local availability of treatment, the WHO estimates that nearly 90% of transfusion dependant patients are not adequately transfused [26]. The need for equity in healthcare is exceptionally important for ST because the quality of chronic management has a direct relation to mortality [27–29]. In India, as the public healthcare sector is beginning to define programs for care and management of hemoglobinopathies [30], there is a need to setup mechanisms to ensure that such interventions reach all sections of society and that critical outcomes are measurable on a regular basis.

We reviewed the experience from five non-profit centres dedicated to providing care and management for thalassemia. These centres use technology-driven healthcare delivery and shared common practices aimed at strengthening the delivery of care to thalassemia patients. Our study evaluates the equity in care achieved at these five centres and proposes a model which could be used to measure equity of care delivery in the context of thalassemia.

## 2. Aim

To evaluate the performance of thalassemia centres in providing equitable healthcare to patients suffering from ST based upon known determinants of health inequity in India.

## 3. Materials and methods

This is a retrospective analysis which compared health indicators associated with ST management on various factors known to contribute to inequity in healthcare for five centres in India, namely Indira Gandhi Institute of Child Health – Bangalore (IGI), Project Samraksha (Rashtrotthana Parishat) – Bangalore (SAM), Thalassemia and Sickle Cell Society – Hyderabad (TSC), Rural Development Trust – Ananthpur (RDT) and Jai Shivshakti Centre for Thalassemia (Jawaharlal Nehru Medical College) – Belgaum (KLE).

Participating centres uniformly used ThalCare™ – an application platform intended to support the end-to-end care and management of ST. The role of ThalCare in management of thalassemia is described elsewhere [31]. Patient demographics, key information associated with their care and management and significant events associated with their treatment were uniformly recorded by each centre on ThalCare in a prospective manner.

IGI is located in a government hospital while the others are located in private non-profit Non-Governmental Organisations (NGOs). IGI, SAM and KLE were supported with financial resources and knowledge-management by Sankalp India Foundation, (a NGO facilitating collaboration for thalassemia management) while the other two centres collaborated with the Sankalp network only for knowledge management.

We chose pre-transfusion haemoglobin (PTH) and serum ferritin level as the health indicator which we could use to measure health equity in care and management of ST. PTH is an indicator of transfusion services while serum ferritin is an indicators of the access and compliance to the critical iron chelation therapy.

We searched PubMed and the grey literature for “social determinants” “non-communicable” and “health equity” etc. to identify the social determinants leading to inequity. Work which specifically related to the issues seen in the LMICs was prioritised. The four chosen social determinants to inequity were the economic status (defined as whether the family was above or below the poverty line), sex, distance from the centre (defined as whether the patient came for treatment from within or more than 150 km) and maximum education of either of the parent (defined as whether the parents received education upto matriculation level<sup>1</sup> or not).

The data available from ThalCare was summarised using Microsoft Excel and further analysed using R (version 3.3.2). Mann-Whitney test was used to determine if the difference between the health indicators across various influencing factors was significant and  $p = .05$  was used as cut-off for statistical significance (see Table 1).

## 4. Results

We measured the equity in healthcare based upon economic background, sex, distance of the centre from patient's house and parental education. A total of 1507 patients and 17929 visits and 2775 ferritin reports between April 2016 and March 2017 were analysed. Table 2 summarises the impact of various social determinants on PTH while Table 3 summarises the impact on ferritin level. Some patients could not be categorised in either group because of missing data and were omitted from the analysis.

**Economic background:** Aggregating all the centres, the PTH was significantly lower for BPL patients ( $p < .0001$ ). In 2 centres the patients from below poverty line (BPL) families had lower median PTH compared to those from above poverty line (APL) families and the difference was very significant only in 1 centre ( $p = .0001$ ). Two centres had same median PTH ( $p = .051$  and  $p = .08$ ). One centre has only those patients who are BPL and hence was omitted from this analysis (see Table 2).

Overall, there was no difference in the median ferritin levels of patients above and below poverty line ( $p = .42$ ). The ferritin level was significantly higher for BPL patients in 1 centre ( $p < .0001$ ) while it was significantly lower in another centre ( $p = .004$ ).

**Sex:** In the whole group, females had significantly better PTH ( $p < .0001$ ). In 4 of the five centres females had better median PTH than males and the difference was significant in all centres,  $p = .046$  to  $p < .0001$  respectively. There was no difference observed in the remaining centre.

Females had lower median ferritin levels in whole group ( $p = .16$ ) and also in 4 of the 5 centres though the difference between ferritin levels between females and males was not significant in any of the centres ( $p = .11$  to  $p = .94$ ).

**Distance:** When all patients were put together the difference in PTH was found to be significant ( $p < .0001$ ), in spite of 4 centres

<sup>1</sup> Matriculation is same as final year of high school or tenth grade.

**Table 1**  
Enrolment information.

	IGI	SAM	TSC	RDT	KLE	Overall
Host institution Setup	Attached to a major academic children's hospital Government	Attached to a standalone blood bank Private (Non-Profit)	Attached to a standalone blood bank Private (Non-Profit)	Attached to a rural hospital Private (Non-Profit)	Attached to a medical college Private (Non-Profit)	
Using ThalCare since	Nov-11	Aug-13	Nov-14	Aug-15	Mar-16	
Number of patients	272	271	707	83	174	1507
Median Patient age (in years)	6.5	9.1	6.6	8.4	8.4	7.7
Age Range (in years)	(0.6 to 23.88)	(0.3 to 44.3)	(0.3 to 45.3)	(0.5 to 15.8)	(0.9 to 26.4)	(0.3 to 45.3)
Patients more than 18 years of age	7 (2.6%)	7 (4%)	0 (0%)	54 (20%)	58 (8.2%)	126 (8.4%)
Economic distribution						
Above Poverty Line	29 (11%)	77 (28%)	52 (7%)	0 (0%)	19 (11%)	177 (12%)
Below Poverty Line	238 (88%)	188 (69%)	608 (86%)	83 (100%)	135 (78%)	1170 (78%)
Sex distribution						
Male	159 (58%)	159 (59%)	418 (59%)	56 (67%)	109 (63%)	901 (60%)
Female	113 (42%)	112 (41%)	289 (41%)	27 (33%)	65 (37%)	606 (40%)
Distance from care centre distribution						
Less than 150km	171 (63%)	199 (73%)	432 (61%)	81 (98%)	158 (91%)	1041 (69%)
Greater than 150km	101 (37%)	72 (27%)	275 (39%)	2 (2%)	16 (9%)	466 (31%)
Parent's maximum education						
Matriculation and above	70 (26%)	124 (46%)	NA	NA	NA	194 (13%)
Below Matriculation	143 (53%)	32 (12%)	NA	NA	NA	175 (12%)

Participating centres uniformly used ThalCare™ – an application platform intended to support the end-to-end care and management of ST. The role of ThalCare in management of thalassemia is described elsewhere [31]. Patient demographics, key information associated with their care and management and significant events associated with their treatment were uniformly recorded by each centre on ThalCare in a prospective manner.

**Table 2**  
Impact of social determinants on pre-transfusion haemoglobin levels across the centres.

Economic Status							
Centre	Above Poverty Line			Below Poverty Line			P Value
	Median	IQR <sup>a</sup>	N	Median	IQR	N	
IGI	9.4	8.6 to 10.3	315	9.4	8.4 to 10.1	2895	.051
KLE	8.7	8.0 to 9.5	272	8.7	7.8 to 9.4	1895	.54
SAM	9.3	8.4 to 10.0	947	9.2	8.4 to 10.0	2124	.08
TSC	8.5	7.8 to 9.3	628	8.4	7.5 to 9.1	6876	.0001
<b>Overall</b>	<b>9</b>	<b>8.2 to 9.8</b>	<b>2162</b>	<b>8.7</b>	<b>7.8 to 9.5</b>	<b>13805</b>	<b>&lt;.0001</b>
Sex							
Centre	Male Median	IQR	N	Female Median	IQR	N	P Value
IGI	9.3	8.4 to 10.1	1945	9.4	8.5 to 10.3	1321	.046
KLE	8.6	7.7 to 9.4	1547	8.8	8.0 to 9.5	879	.003
RDT	9	8.0 to 9.9	731	9	8.0 to 9.8	309	.8
SAM	9.1	8.3 to 9.9	1875	9.4	9.3 to 9.5	1229	<.0001
TSC	8.3	7.5 to 9.1	4822	8.5	7.6 to 9.2	3075	<.0001
<b>Overall</b>	<b>8.7</b>	<b>7.8 to 9.5</b>	<b>10920</b>	<b>8.9</b>	<b>8.0 to 9.7</b>	<b>6813</b>	<b>&lt;.0001</b>
Distance from home to treatment centre							
Centre	Less than equal 150 km			More than 150 km			P Value
	Median	IQR	N	Median	IQR	N	
IGI	9.4	8.5 to 10.1	2055	9.4	8.5 to 10.1	1211	.68
KLE	8.7	7.9 to 9.4	2240	8.7	7.6 to 9.5	186	.68
RDT	9	8.0 to 9.9	1019	9.4	7.7 to 10.0	21	.89
SAM	9.2	8.4 to 10.0	2353	9.2	8.1 to 10.0	751	.37
TSC	8.5	7.6 to 9.2	5131	8.2	7.4 to 9.0	2766	<.0001
<b>Overall</b>	<b>8.8</b>	<b>7.9 to 9.6</b>	<b>12798</b>	<b>8.6</b>	<b>7.7 to 9.6</b>	<b>4935</b>	<b>&lt;.0001</b>
Highest education of parent							
Centre	Matriculation and above			Up-to Middle School			P Value
	Median	IQR	N	Median	IQR	N	
IGI	9.4	8.5 to 10.1	851	9.4	8.5 to 10.1	1743	.99
SAM	9.2	8.4 to 9.9	1331	9	8.1 to 9.8	415	.01
<b>Overall</b>	<b>9.3</b>	<b>8.4 to 10.0</b>	<b>2198</b>	<b>9.3</b>	<b>8.4 to 10.1</b>	<b>2231</b>	<b>.2</b>

<sup>a</sup> IQR: Inter-quartile range.

**Table 3**  
Impact of social determinants on median ferritin(ng/ml) levels across centres.

Economic Status							
Centre	Median	IQR <sup>a</sup>	N	Median	IQR	N	P Value
	Above Poverty Line			Below Poverty Line			
IGI	2580	1845 to 3730	63	2320	1598 to 3280	577	.1
KLE	4170	2015 to 5642	63	2670	1664 to 4635	425	.004
SAM	2556	1738 to 3670	227	3356	2188 to 4377	560	<.0001
TSC	2513	1461 to 3383	37	2818	1814 to 4230	382	.06
<b>Overall</b>	<b>2681</b>	<b>1764 to 3897</b>	<b>390</b>	<b>2745</b>	<b>1760 to 4060</b>	<b>1947</b>	<b>.42</b>
Sex							
Centre	Male Median	IQR	N	Female Median	IQR	N	P Value
IGI	2400	1690 to 3365	388	2260	1520 to 3300	262	.11
KLE	2986	1731 to 4867	355	2728	1699 to 4923	201	.45
RDT	2598	1458 to 4324	154	2367	1600 to 3222	68	.11
SAM	3046	1960 to 4203	473	3240	2021 to 4153	335	.7
TSC	2812	1805 to 4184	269	2792	1804 to 4057	164	.94
<b>Overall</b>	<b>2740</b>	<b>1772 to 4130</b>	<b>1639</b>	<b>2710</b>	<b>1729 to 3930</b>	<b>1030</b>	<b>.16</b>
Distance from home to treatment centre							
Centre	Less than equal 150 km			More than 150 km			P Value
	Median	IQR	N	Median	IQR	N	
IGI	2320	1583 to 3508	455	2415	1660 to 3280	238	.95
KLE	2886	1738 to 4916	517	2240	1585 to 4210	44	.15
RDT	2443	1473 to 3891	215	3239	2253 to 3810	7	.41
SAM	3090	1944 to 4144	657	3009	1974 to 4138	188	.62
TSC	2732	1672 to 3992	280	2919	1956 to 4360	174	.15
<b>Overall</b>	<b>2742</b>	<b>1738 to 4090</b>	<b>2124</b>	<b>2680</b>	<b>1775 to 3913</b>	<b>651</b>	<b>.47</b>
Highest education of parent							
Centre	Matriculation and above			Up-to Middle School			P Value
	Median	IQR	N	Median	IQR	N	
IGI <sup>b</sup>	2545	1850 to 3610	182	1965	1440 to 2930	362	.0001
SAM <sup>c</sup>	2781	1753 to 3864	335	4260	3431 to 4826	97	<.0001
<b>Overall</b>	<b>2634</b>	<b>1770 to 3793</b>	<b>520</b>	<b>2323.5</b>	<b>1560 to 3820</b>	<b>478</b>	<b>.24</b>

<sup>a</sup> IQR: Inter-quartile range.

<sup>b</sup> Median age: 5.6 years IQR: 2.8–9.8 years.

<sup>c</sup> Median age: 9.8 years IQR: 4.8–15.2 years.

showing no adverse impact of distance. There was no difference seen in PTH for patients coming from distances more and less than 150 km away from the centre in 3 of the 5 centres ( $p = .37$  to  $p = .68$ ). In one centre median PTH was higher for the patients coming from more than 150 km away though it was not statistically significant ( $p = .89$ ). In the remaining centre, PTH was significantly lower for patients from distances more than 150 km ( $p < .0001$ ).

The number of visits for blood transfusion per year were significantly lesser ( $p < .0001$ ) for patients coming from distances more than 150 km for the whole group. The centre which had a significant difference in the PTH was also the one which had significantly different number of visits per year ( $p < .0001$ ).

Similarly, the overall group showed no impact of travel on median ferritin levels ( $p = .47$ ). Patients travelling from more than 150 km away had slightly higher ferritin levels in 3 centres but the difference was not significant in any of the 5 centres ( $p = .15$  to  $p = .95$ ).

**Education level:** Data on parental education was available only from 2 of the 5 centres for a limited number of patients. The whole group showed no significant difference ( $p = .2$ ). Children of parents who received education of matriculation or above had similar median PTH in 1 centre ( $p = .99$ ) while it was significantly higher in the other centre ( $p = .01$ ).

Overall, no impact of parental education on ferritin was observed ( $p = .24$ ). Median ferritin was significantly higher for patients from more educated families in 1 centre ( $p = .0001$ ) while

it was significantly lower in the other centre ( $p < .0001$ ).

## 5. Discussion

Technology-driven management of thalassemia enabled structured review of the outcome of care being delivered on various determinants of social inequity retrospectively.

### 5.1. Impact of economic status

As reported elsewhere [3,20] economic status is expected to create significant gaps in access to healthcare but three of the four centres did not have significant impact of economic status on PTH. The overall impact on PTH is significant because of the larger number of patients in the only centre where inequity was significant. Equity may have been achieved because provisioning of blood, blood transfusion and hospitalisation was free of cost for all patients in each of the five centres. Transportation support was also provided to needy families in two centres. Wherever possible, help to ensure availing existing travel benefit schemes from Indian Railways was provided to families.

In-line with our findings, given the fact that blood is to be issued free of cost to patients suffering from thalassemia, economic differences should not lead to inequity in PTH. However, a study by Moirangthem et al. from Sanjay Gandhi Postgraduate Institute of Medical Sciences, Lucknow [32], reported inadequacy of blood transfusions – and linked it to economics. Other reasons like

difficulties in blood provisioning, transfusion policies etc. may be contributing to inadequacy of blood transfusions rather than economic reasons.

Ferritin level did not seem to be impacted by economic status. Each of the centres provided free chelation drugs to patients who could not afford the same while more well-off patients were expected to cover the cost of drugs. This may be the reason why one of the centres reported lower ferritin levels for BPL patients who are more likely to be on proper chelation. ThalCare enabled tracking of the purchase pattern of chelators against the prescribed doses and the inability to buy adequate chelators was used as a factor to decide who should be supported. The absence of universally available free chelation therapy was a vulnerability and may have contributed to the high ferritin levels seen in patients regardless of socio-economic status [33].

### 5.2. Impact of sex

Girls outperformed boys in PTH while no significant difference was seen in the serum ferritin level. While sex-based inequity did not show in the children being treated, there were only 2 females for every 3 males, indicating a potential bias against girls at recruitment itself.

### 5.3. Impact of distance

Distance from the point of care also failed to cause inequity in all but 1 centres as far as PTH is concerned. That there was no inequity was seen in terms of ferritin levels in any centre may also be because ferritin is less likely to be influenced by distance. Two centres provided transportation support to patients who were found to miss their appointments because they did not have money to travel. Some patients also used the concession provided by Indian railways [34]. The fact that the centres deliver care within a few hours (typically 8 h for each patient) ensure that the overall loss of work for families of even those patients who need to travel significantly is not more than a day. The centre where inequity was seen in PTH related to the distance travelled by the patient did not have any specific interventions in place to bridge this inequity.

This finding is important for choosing between more specialised and better-equipped centres for management of chronic illnesses versus providing care in the vicinity. Our experience and belief has been that it is better to have centres which deliver better quality of care even if they are at a considerable distance, if assistance is available to travel for patients who need it. Our observations seem to suggest that this approach does not adversely impact health outcomes. Centres located in places which have large blood banks competent to attend to the specific blood requirements of thalassemia patients, with adequately and specifically trained staff and high volume of patients seeking treatment seem to do better in our experience.

### 5.4. Impact of education level

Though three centres did not track the education of the parents, the overall experience from the remaining two shows no impact of parental education on health outcomes. These centres provide end to end care for thalassemia under one roof with patient's clinical status and history being tracked by the centre independently of the parents having to maintain records or give reminders. This approach may have significantly mitigated the negative impact of poor education on the ability of the parents to ensure proper treatment [35]. The centres also had fixed staff nurses who were specifically trained to counsel families and keenly watch out for common problems that may affect treatment of the child. We

believe staff that are trained, motivated and made a significant stakeholder to cater to the unique needs of a specific disease condition are deployed, gaps arising out of limited education and ignorance are bridged.

### 5.5. Variation between centres

Four of the five centres involved in the study started in last 6 years. There are significant differences in the age group of the patients they attend to and the status of iron overload at the time of recruiting patients (Fig 1). There are some customizations in the delivery of agreed upon clinical management strategies at some of the centres [36]. Thus inter centre variation has been kept outside the preview of this study.

Although half or more of transfused patients had critically high ferritin levels in excess of 2500 ng/mL, each one of the centres has shown a consistent drop in the average serum ferritin levels on a year on year basis (Fig 1). It may take a few more years of sustained chelation therapy to bring the serum ferritin to acceptable levels. Both health indicators, PTH and ferritin seem to agree, confirming the success of these centres to achieve significant health equity. The reliability demonstrated by our approach across centres holds promise for improving healthcare equity across the developing world and within resource-limited settings. Our experience demonstrates that equity can be achieved even against deep rooted social gradients like economic status, sex, distance of travel and parental education status.

### 5.6. Factors that may have contributed to equity

It's hard to say whether equity was seen because these centres did not burden the families with the cost of care or due to other factors. Blood transfusions and lab investigations were free for all patients. Families were provided food while they waited to receive care. The appointments were communicated in advance and the treatment delivery happened swiftly once the patient arrived. One of the centre worked on Sundays to ensure that patients who need more frequent follow-ups don't lose upon academics and work. All these interventions may have contributed to unburdening families.

Our analysis is biased towards low-resource centres where care and management was largely supported by the treating hospital or non-profits. The experience involves mostly paediatric patients and

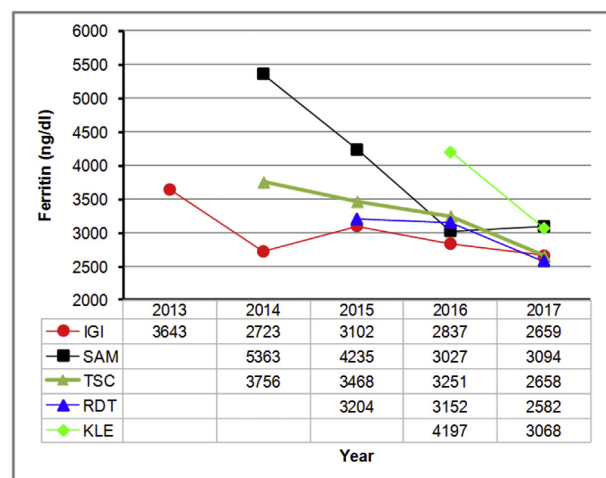


Fig. 1. The figure shows the mean ferritin levels for the participating centres. Consistent drop has been seen in last few years.



even young adult patients who were mostly taken care of by their parents. Further work is needed to quantify the contribution of each intervention that may have led to health equity. Four of the five centres have started in the last 6 years. We acknowledge that more work remains to be done to bring median PTH and serum ferritin levels in the clinically advisable ranges in most of the centres. This is a steep challenge with constant enrolment of new patients who may have received little or no treatment before.

## 6. Conclusion

The centres included in this survey have been able to achieve health equity based on social determinants including economic status, sex, travel distance to the centre of treatment and education level of parents. This experience shows how health outcomes could be measured based upon factors contributing to inequity and that health equity can be achieved even in resource-limited setting for management of chronic diseases like thalassemia.

## Conflicts of interest

None.

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