

# FACIAL CLEFT PROJECT



## Impact Assessment Report

**PERSISTENT SYSTEMS LTD.**



### Third-Party Impact Assessment

Conducted by Chhaaya Strategic Advisors, LLP

May 2024



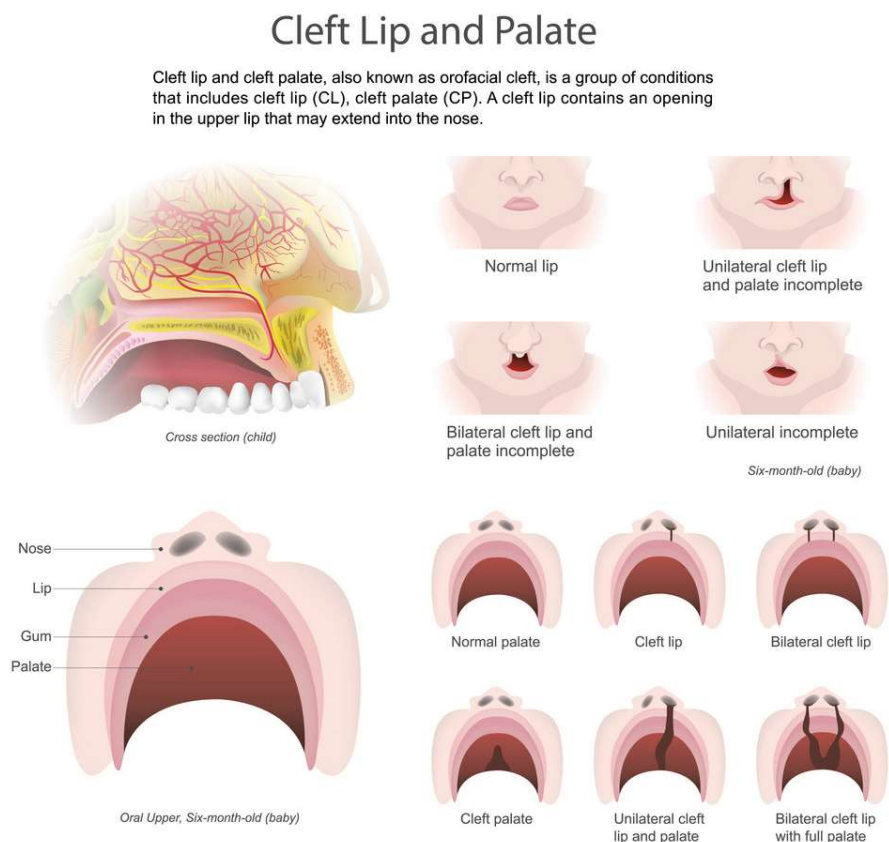
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## 1. INTRODUCTION

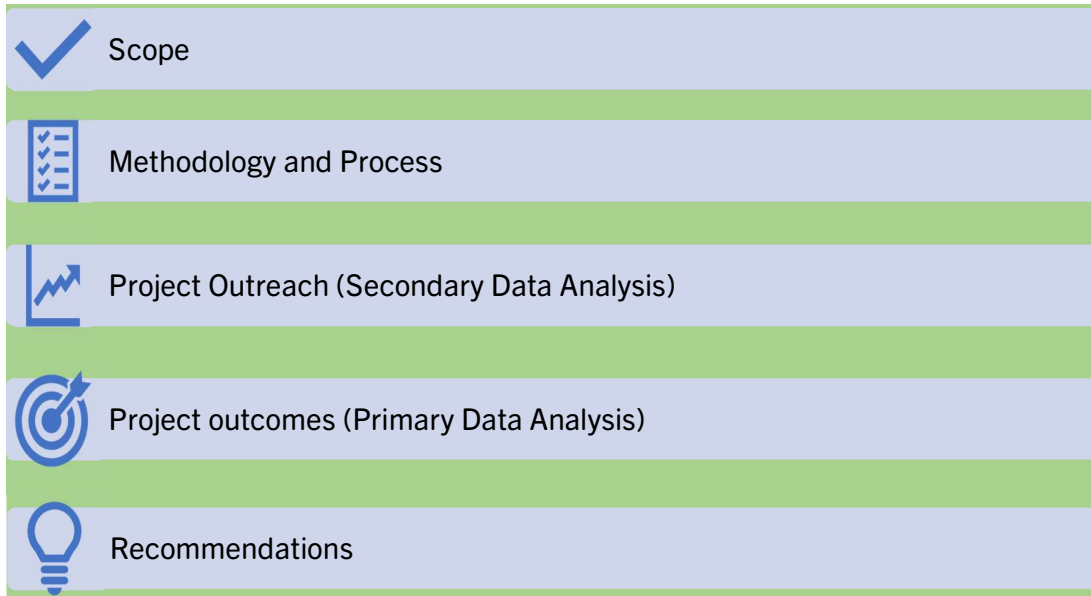
Since last few years, ‘Facial Cleft Surgeries and Comprehensive Care’ (facial cleft) program has been a funded flagship CSR program of Persistent Systems Ltd. (PSL), with the largest funding. It began in 2016-17 and has had growing outreach every year since then. What began as a response to a specific problem, in the form of partial help for surgeries, has now become a comprehensive care program, encompassing all aspects of health and services related to facial cleft issues. In the last couple of years, the budget outlay has also grown considerably. Hence, third-party assessment as directed by Companies Act 2013’s CSR provisions has become mandatory. PSL engaged Chhaaya Strategic Advisors LLP (Chhaaya) to carry out the assessment for the financial year 2022-23.

This report is based on the impact assessment conducted by Chhaaya.



## 2. IMPACT ASSESSMENT PROCESS

The report contains:



Since the program began in 2016-17 and impact assessment has already been conducted twice (first time in 2017-18 and second time in 2022), some analytical comparisons have also been included in this report.

### Scope

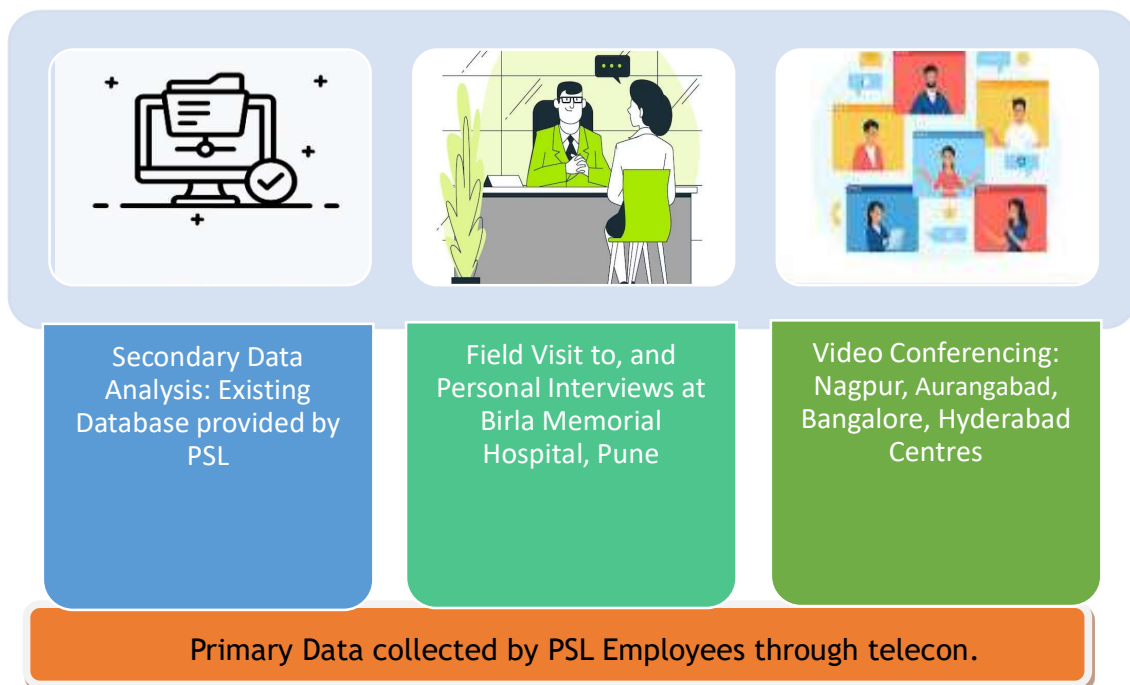
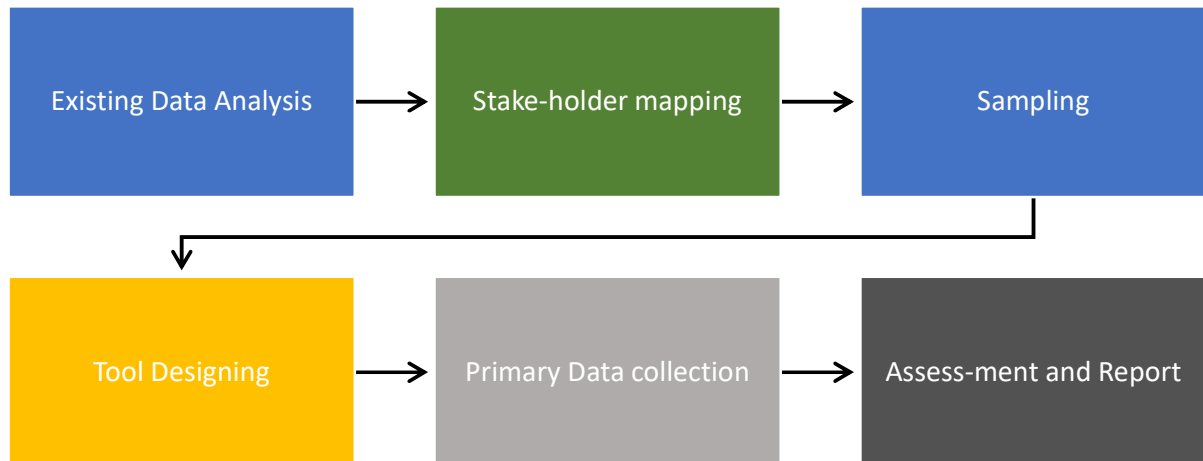


The centres covered for analysis under this impact assessment are Hyderabad, Bangalore, Aurangabad, Pandharpur, Nagpur and Pune. Though the focus is primarily on assessing the project performance of the year 2022-23, some comparisons with earlier years in important aspects are also presented in this report. Similarly, recommendations given in the earlier reports and their implementation are also looked at from the point of view of improvement of the overall program.

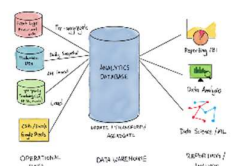
## Methodology and process



Methodology of assessment included designing the questionnaires for various stakeholders (structured as well as semi-structured). The following table lays out the detailed methodology adopted for various stakeholders.



## 1. Project database analysis: PSL has maintained an excellent database of the cleft



patients. The first task was to analyse this data which gave important perspective on various aspects of the patients including their economic and social background. Primary data collected through volunteers (they conducted telephonic interviews for which questionnaire was developed). The stakeholders for primary data collection were identified by PSL along with the doctors in the various locations.

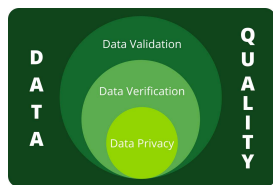
## 2. Stakeholder Interviews by PSL volunteers: They conducted 54 telephone



interviews with the selected patients. These were conducted using structured questionnaires, which included the following aspects:

- Coverage (centre-wise survey done)
- Social (age group, family type, siblings, caste, religion, etc.) and Economic status of the patients treated.
- Reactions to and perception about the deformity
- Choice of the hospital / agency for treatment (information source, reasons for choosing this agency, etc.)
- Surgery and treatment (duration, no. of surgeries, other services, etc.)
- Financial aspects (cost of treatment, financial support, expenditure incurred, etc.)
- Effects of surgery (changes perceived, experience of the agency, recommendation)

## 3. Validation by Chhaaya: Dr. Anagha Joshi from Chhaaya team verified the



secondary and empirical information through a visit to Birla Hospital in Pune, where surgeries are conducted; and in-person interviews of the patients to understand qualitative aspects of the project and beneficiary experiences.

**Validation Telephone Calls by Chhaaya:** Since the data had been collected and analysed in the year 2022-2023, validation calls were made by Dr Anagha Joshi to randomly selected direct stakeholder to see whether the findings of 2023-2024 were consistent with the opinions shared by the beneficiaries in 2024-2025. The primary data and opinions shared by the beneficiaries was found to be consistent with the earlier findings.

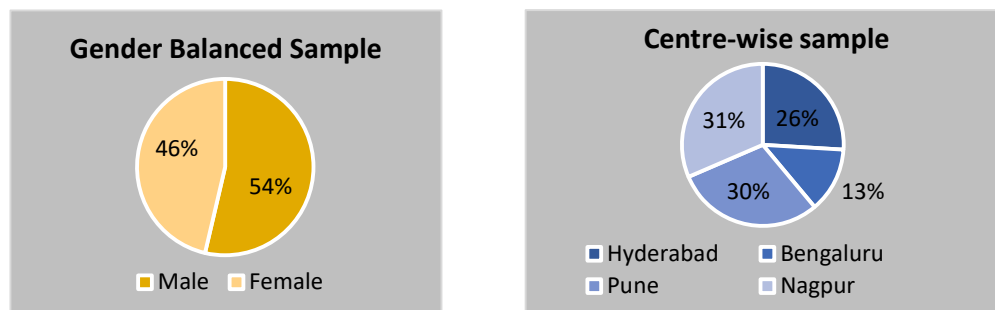
Method	Tools	Stakeholder Respondents
<b>Video conferencing</b>	Semi Structured Questionnaire	<ul style="list-style-type: none"> <li>• Dr Darshan Ramkrishna Rewanwar + 1 Nagpur - Nelson Mother and Child Care Hospital</li> <li>• Dr Ujwala V Dahiphale, Aurangabad - Dahiphale Hospital</li> <li>• Dr. B.S. Jayanth, Bangalore -Rangadore Memorial Hospital</li> <li>• Dr A Vijay Kumar Hyderabad - AVR Dentofacial Hospital</li> </ul> <p>13 beneficiaries in total from all the above Centers participated in the video call.</p>
<b>Personal Interviews</b>	Semi Structured Questionnaire	<ul style="list-style-type: none"> <li>• Dr Sagar Jangam, Birla Memorial Hospital, Pune</li> <li>• 2 beneficiaries from the hospital</li> </ul>
<b>Telephonic interviews</b>	Structured Questionnaire	<ul style="list-style-type: none"> <li>• Telephonic interviews of the parents / caretakers as identified by each Centre, by PSL employees - total 53 interviews.</li> </ul>

### Sampling:

PSL invited employees to volunteer for tele-interviews of the parents or their caretakers. The questionnaire was designed, and each employee was asked to ask questions accordingly. This helped to keep uniformity in the data collection.

Apart from that, each centre invited a few parents/caretakers with the patients to the

video conference so that the assessment team could talk to them directly. The number of the patients to be called was the centre's decision.



### **Limitations:**

There were a few constraints in collecting empirical information regarding the direct impact of the programme. Due to the unavailability of beneficiaries, surveys could be conducted in only 4 centres. Aurangabad and Pandharpur were dropped as surveys could not be conducted there.

There were some genuine hurdles for parents and patients to come to the clinic at the centres - such as heavy rains in Hyderabad, agitations for Maratha reservations in Maharashtra, etc. This resulted in reduction in the sample, we could not get as many interviews through the video conference as planned. For telephonic interviews, many phone numbers were not reachable or had been changed. All this put severe constraints on reaching the parents/caretakers of the patients.

## **3. THE PROJECT<sup>1</sup> PERFORMANCE**



Cleft program is being supported by PSL since 2016-17. Impact assessment of this program was conducted in 2018, 2022 and 2024. The comparative graph indicates how the outreach has been growing each year over the years.

<sup>1</sup> The project is often referred to as programmes in this document. Chhaaya considers it more than a project, as it includes several interventions; and these are ongoing, not time bound.

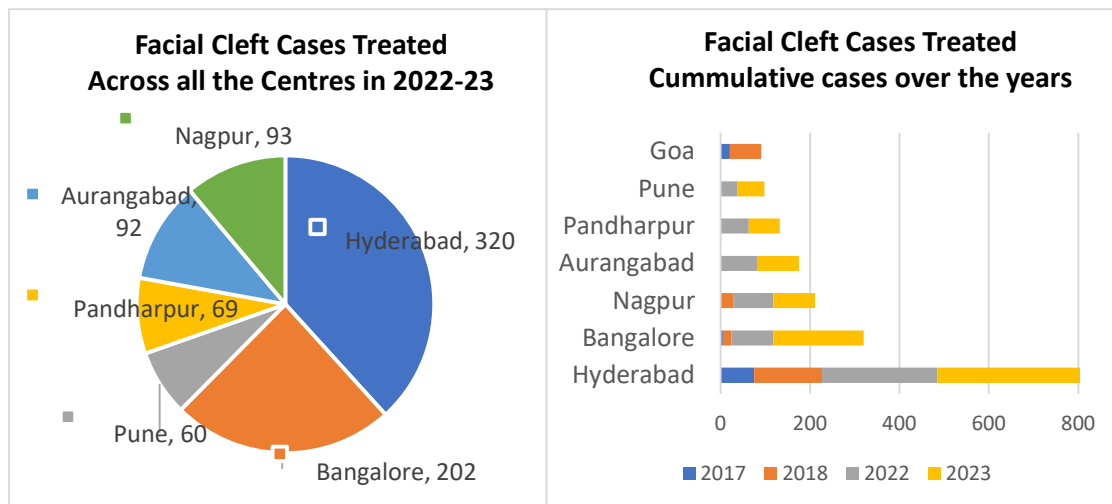


## A. Significant outreach:

The programme outreach has significantly increased, particularly focused on the most disadvantaged sections of society:

### *Continue to reach the unreached....*

Based on the secondary data, there was 170% percentage increase in the outreach of the project from the year 2017 to 2018. In the succeeding 4 years, from 2018 to 2022, it was

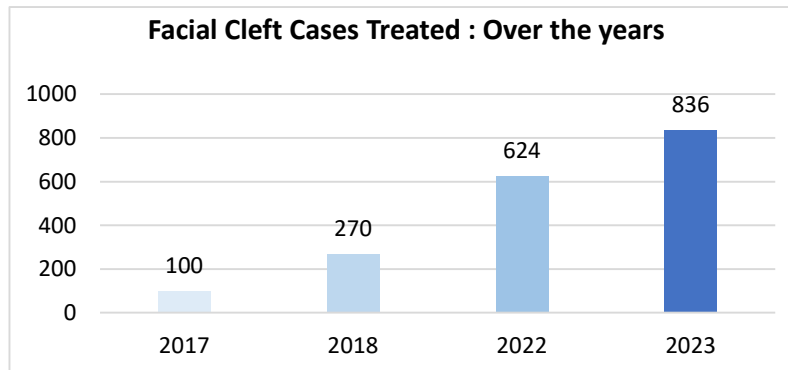


131%! This trend continued in the year current year too. In 2022-2023, the number of cleft surgeries has grown by 34%. Given that the incidence of Facial cleft has not increased, ever expanding outreach is commendable! This is an incredible performance in the consecutive 7<sup>th</sup> year!!

The outreach has been varying across the centers, it is both an outcome of the delivery model (who is the collaborating partner), need and the budget outlay. The data indicates that Hyderabad always had the highest number of cases. It is owing to the following reasons.

1. Hyderabad was the first centre for which support was provided, all the interventions evolved here. This centre gave boost to other centres.
2. The extension activities for identifying the patients are more effective here, which is reflecting in better outreach,

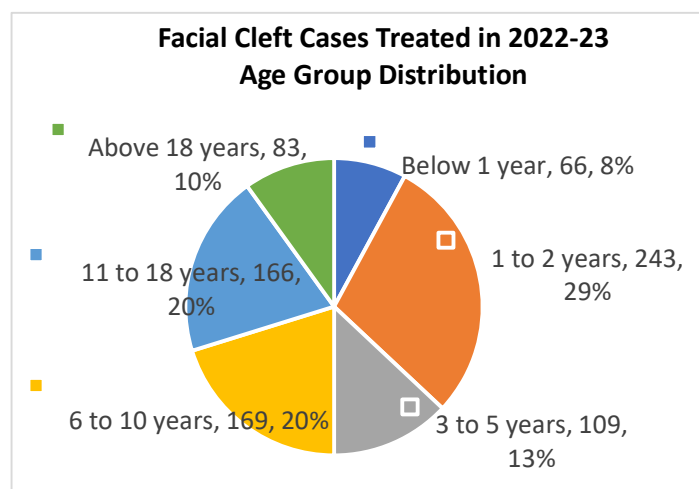
3. It is likely that, there a higher incidence of cleft lip and palette in the state.



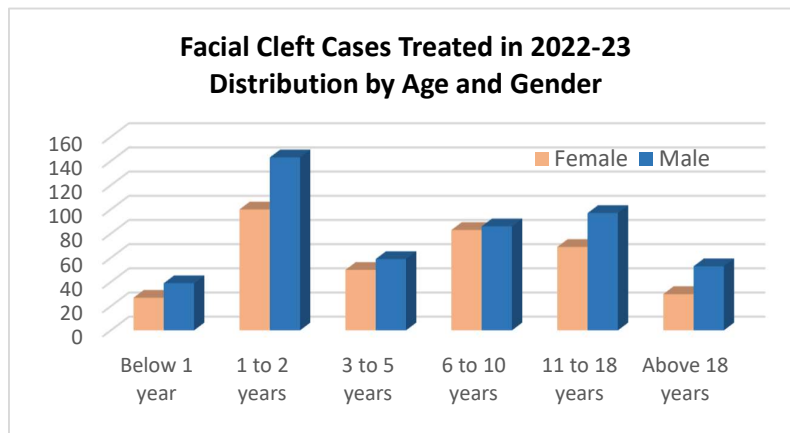
Goa was dropped after 2018 and Pune, Aurangabad and Pandharpur were added from 2021-22 onwards. No clear justification was available for this besides funds rationalization.

### *Catching them young....*

The success of the project is in identifying the patients as early as possible, as it helps to ensure full recovery. It is recommended that the lip cleft surgery be done at the age of 6 to 7 months and cleft palette surgery be done at the age of 9 to 12 months provided the babies are not malnourished and have gained adequate weight. As the babies are born with the defect, reaching out and identification becomes very important. If the first surgery is done later than at 2 years of age, some speech defects may not be possible to overcome.

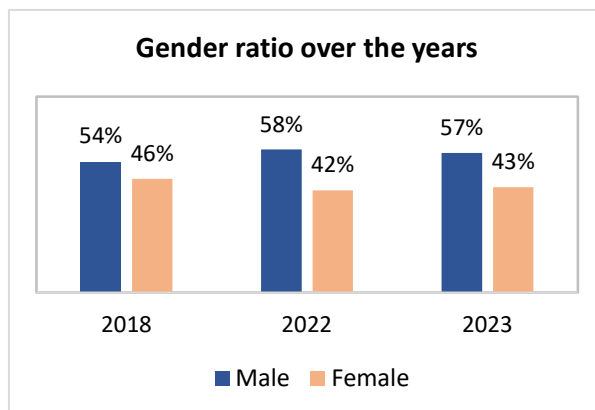


The data shows that timely detection has been possible only in 37% of the cases. However, there much more scope in increasing this percentage. Identifying babies at earlier age for surgeries, so that there is near complete recovery.



***Tie-up with district hospitals and Rashtriya Bal Suraksha Yojana are helping to identify patients sooner / immediately after birth.***

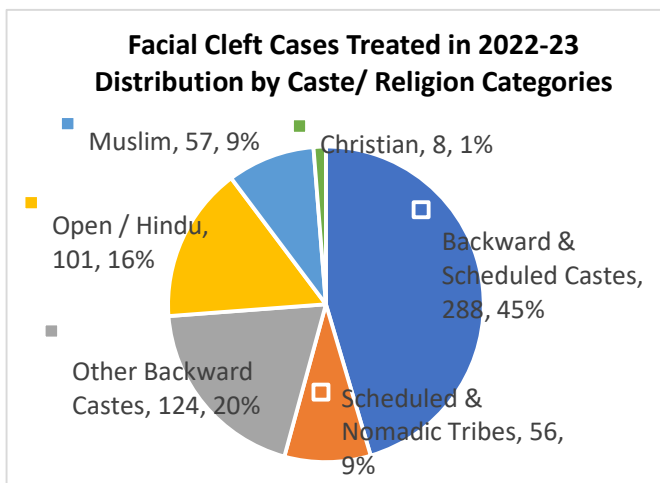
### ***Slightly higher incidence of deformity in male children....***



At the first glance, one may be inclined to assume that there is a bias in favour of a male child for treatment. However, the surgeons mentioned that the world data indicates that the male children are more likely to suffer from gene mutation than girl children, though the difference is not very significant.

### Reaching out to marginalized and vulnerable....

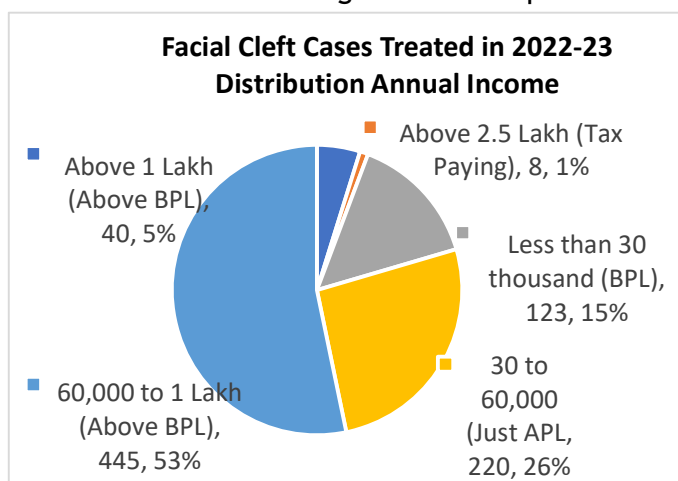
Caste<sup>2</sup>, which indicate disadvantaged sections of society are covered better through the project. It is possible that (a) SC/STs have the highest incidence of deformity, followed by BC and OBC, which could mean there is direct relation of the deformity to the social strata to which the parents belong. The percentages remain similar over the years. Or (b) the cases among the upper castes / class access treatment in private hospitals, of which no data is available.



In any cases the project is certainly beneficial to the needy, as the highest outreach is amongst those who are from socially disadvantaged sections.

### Helping those who need it the most....

Nearly 80% of the patients come from lower economic background. 15% patients are from the “below the poverty line”<sup>3</sup> backgrounds, only 1! From the tax paying bracket. Majority of them are just above the poverty line.

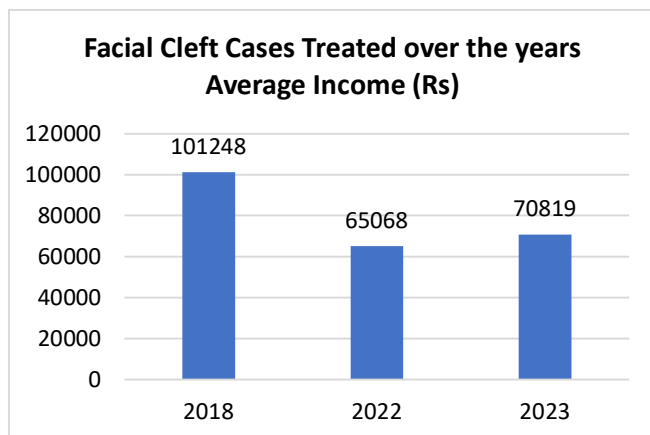


<sup>2</sup> It must be noted that disclosing caste is not made mandatory, it is recorded only if given voluntarily and 25% of the cases have not disclosed this information.

<sup>3</sup> According to the methodology authorized by the Union Cabinet, the BPL income limit in India is around Rs. 27,000 per year. A benchmark known by the Indian government as “below the poverty line” is used to reflect economic losses and to identify people and households in need of support and assistance. It is calculated using various factors that vary both within and between states.

Efforts to reach out to lower income group reflects in the average family income of patients' families'. Over the years more cases are covered from economically weaker sections of society. The average Family income has been brought down and remained

less than Rs 1 lakh per annum.



The patients continue to come from low-income strata families. The major reasons cited for this deformity are marrying within relations, malnutrition, smoke inhalation, etc. are more likely to be prevalent in low-income families. Besides, it is likely that the higher income earning

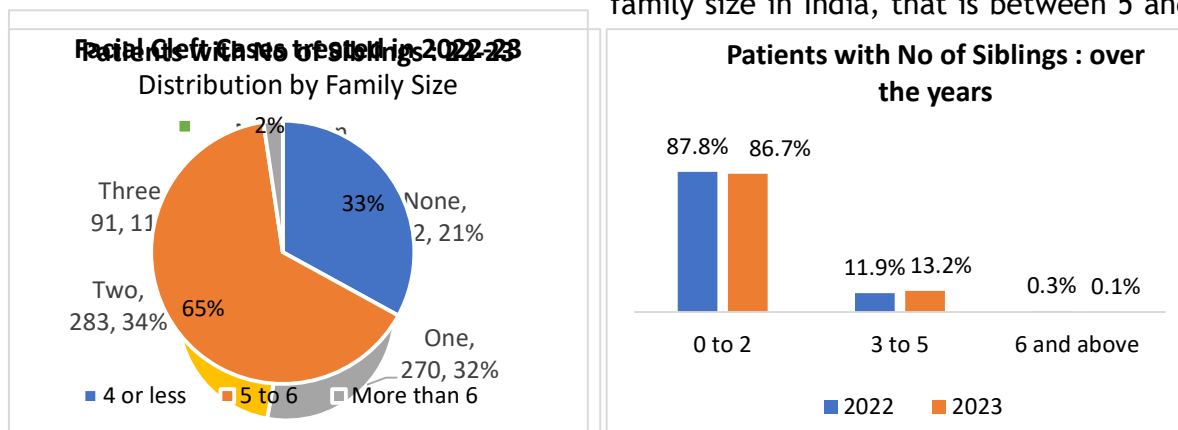
families seek treatment in private hospitals and do not approach agencies for free treatment.

A large majority of the patients (89-90%) come from families with just one earning member, and this has been consistently so, since 2017.

It is possible that the poorest of the poor are still unreached, but the help is certainly going more at the bottom of the pyramid.

### *Smaller families more amongst the beneficiaries ....*

**Family Size and Siblings:** Most of the patients come from families that fall into average family size in India, that is between 5 and

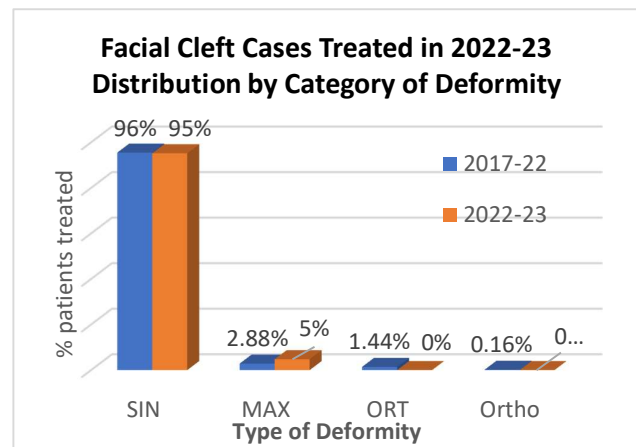


6 members. It can be assumed that these are joint families. As couples having children with such deformities, are keeping their offsprings limited, fearing that more children would be born with similar by default. Often grandparents come to support them. The ratio of cases from these family sizes has remained similar over the years. Number of siblings explains this better.

## B. Effective Interventions

### *Complete recovery in Singular (SIN) deformity cases ....*

More than 95% cases are of singular category, which means that the deformity is minor are resulting in full recovery. During the year 2022-23, there were no cases from ORT and Ortho categories like in the previous years.



### *Dynamic efforts of the Committed implementing team ....*

The impact assessment team interacted with surgeons, beneficiaries, and PSL CSR team. Following observations are made from these interactions:

- Cases have increased in Nagpur. ABMSSS is also supporting with nutrition packets which are being distributed in villages. Though number of cases have increased, quality is also maintained. Recently, speech therapy has also started in this centre.
- In Hyderabad, focus is now on treating primary patients instead of doing corrective surgery for the cases treated by other doctors. The results for corrective surgery were not very satisfactory because a) repeated surgeries were required, b) it was more difficult to do corrections, c) outcome was not guaranteed and hence, d) it was waste of time. Due to all these reasons, 70% to 80% of the patients are now primary cases. Earlier close to 50% cases were of corrective surgeries.

- They are identifying patients by keeping in touch with Govt hospitals and come to know immediately after the baby is born.
- Marathwada is more prone to malnutrition due to economic backwardness. However, the efforts are being made to generate awareness on CLP in public - particularly rural areas. Due to this, the cases are going down. This is more prominent post COVID. International NGOs are also working on awareness generation. LIONS Club organizes surgery camps and invites international surgeons. However, they operate only on lip. Other complex cases are not handled by them. The tendency among people is to prefer international doctors. Many times, even the patients registered in the centre go to these camps.
- In Pune, there is a special OPD for cleft patients in Birla Memorial Hospital. A separate ward is also allotted to these patients. However, the cases have gone down almost by 30% in 2022-23.
- Efforts are being made for awareness generation and identification through referrals.



## C. Beneficiary satisfaction

### *Greater awareness about the availability of treatment*

More than 60% of the patients were below the age of five, indicating that the parents are accessing treatment at an earlier age. It also means that they know that treatment is available and who they should approach. Most of the patients are coming from smaller families, with less support system and for them approaching treatment centers is challenging, yet the access is improving.

### *Likely correlation between facial cleft and consanguineous marriages.*

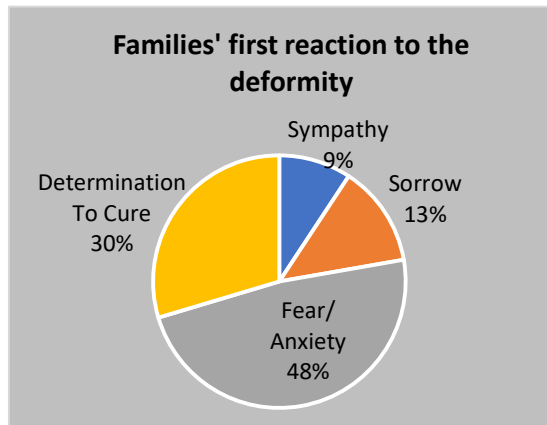
The percentage of parents marrying within relations continues to be around 20%. This means that there still needs to be concerted efforts to generate awareness on inter-

relation marriages. The system is more prevalent in lower castes among Hindus and Muslims.

### ***Fathers give more time for treatment and follow up ...***

50% of the respondents said that the main caretaker of the child having cleft was father, 43% said it was the mother and in 7% cases it is a close relative. This may reflect that the role of caretaker is changing, and fathers feel equally responsible to take care of the child, but it is more likely due to the fact that these children need more travels, hospital rounds and mothers are less mobile, and have domestic responsibilities.

### ***Fear and anxiety were foremost reactions...***

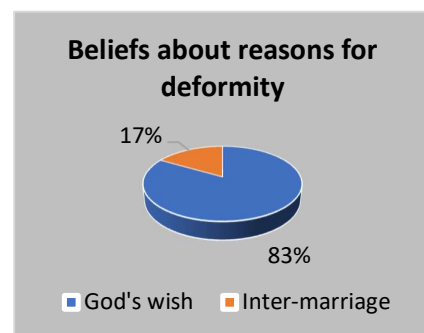


The respondents mentioned that fear and anxiety were the foremost reactions on learning about the deformity either during the later stage of the pregnancy or at birth.

This was followed by determination to cure as the consulting doctors all mentioned to them that cure was available in form of surgery and treatment, and that too, free of cost.

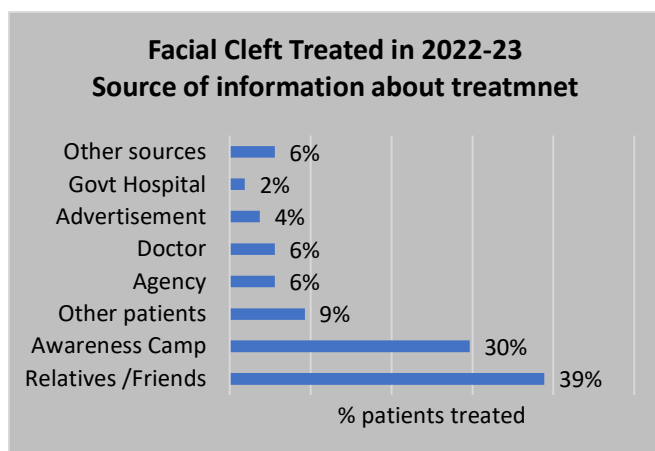
### ***God wanted it this way...***

On the question about why they thought this type of deformity should occur, most of them thought that it was God's wish. There was absolutely no awareness on scientific reasons why it should happen and whether it could be avoided in their next child. This perception also helps in dealing with the issue, that if god has given us a problem god will help solve it too!





### *Different sources from where the families learnt of the treatment...*

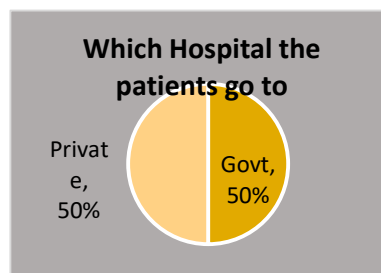
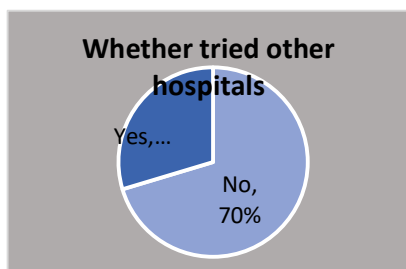


The biggest and most effective way the families (39% of the total) learnt about the hospital and treatment was from someone they knew - either another relative or friends who had been there. This means that 'word of mouth' advertisement is most effective. Another important source was the awareness camps held at

village levels. However, only 37% of the respondents said that they had attended the awareness camp, while 63% had come directly for treatment. It would be better to cover as many patients as possible through awareness camps.

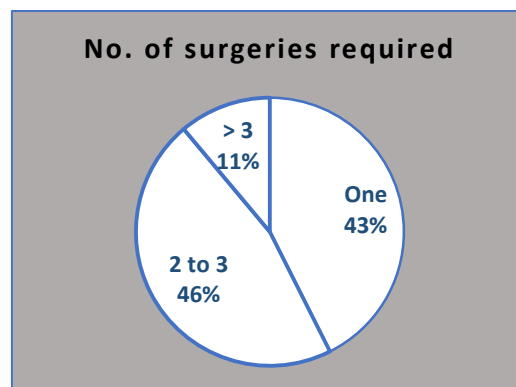
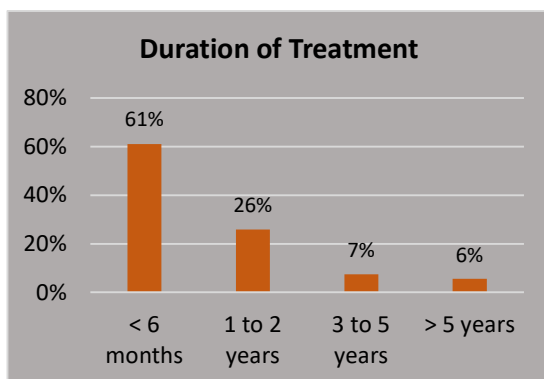
### *This was the first choice for treatment...*

70% of the respondents mentioned that they came straight to this centre for treatment. Among those who had tried other hospitals or treatment centres, 50% were govt and 50% private hospitals.



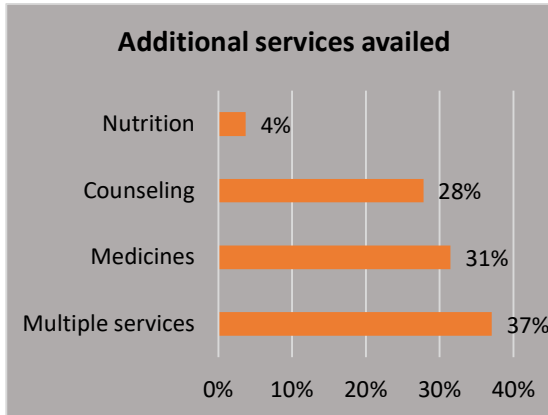
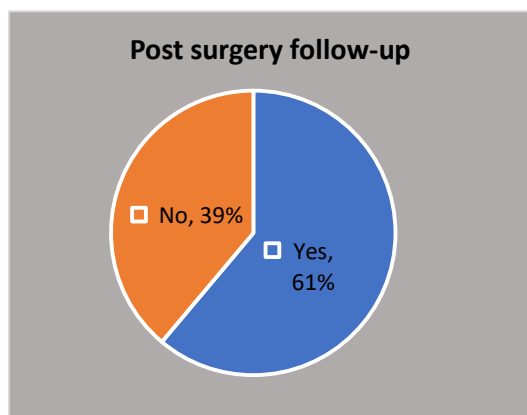
### *Credit goes to early detection and treatment ...*

Duration and treatment differed for each patient depending upon when they first went for the treatment. For the babies who got operated for cleft as well as palette before, or around when they were a year old, i.e., before they learn to speak, speech therapy was not required. If the surgery was done later, speech therapy would also be required. The later the first surgery takes place, the more are the complications.



61% of the respondents said that the duration of the treatment was less than 6 months; and 43% said that they needed only one surgery.

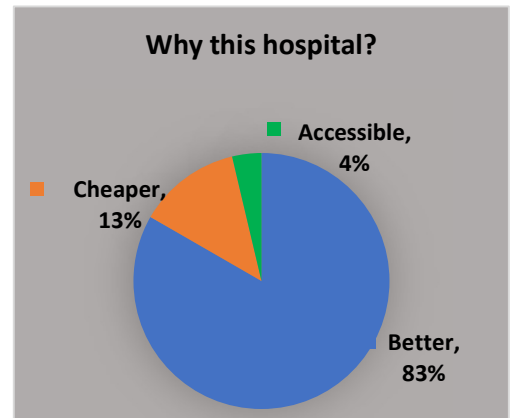
### *Multiple services offered...*



61% of the patients received post-surgery follow up - whether related to further treatment, food and nutrition advice, medical advice, or planning for next surgery. Almost all patients were benefitted from other services required for full recovery.

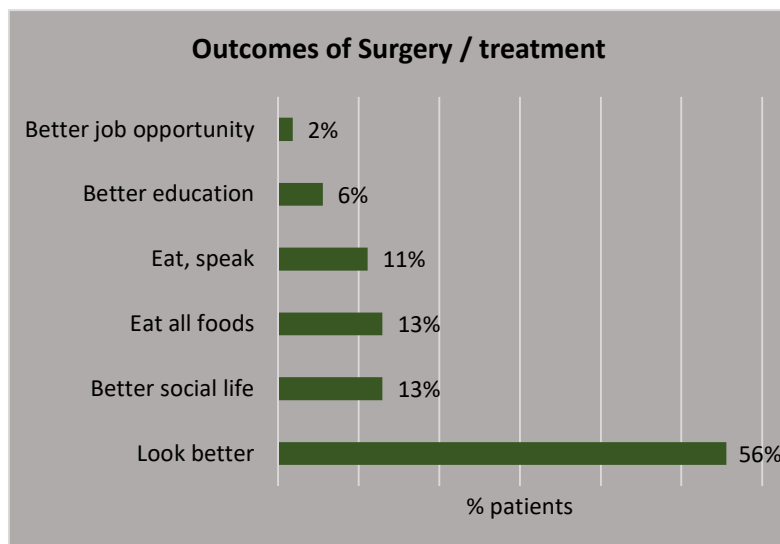
### *This was the best option available...*

83% of the patient families reported that these (project supported) facial cleft treatment centers are the best option available. They opined that the doctors were competent and kind, and the hospital where they got treatment were well equipped. They said that they came to this doctor/hospital because he/it was better than the others. 13% admitted that the entire treatment was cheaper (the treatment was free of cost, but there may be other costs such as travel, stay for the family, food, etc.) here; and 4% said that it was more accessible.



### *Transformative experiences ...*

The families of the patients had had a range of emotions and anxiety after the birth of their child. There were worries about their health, education, prospects in life and how to come to terms with the deformity. There were some who had known before the birth that their child may have this type of deformity and it is treatable free of cost. Some went from pillar to post to find the treatment and how much it would cost. Some accepted it as wish of God and did nothing about it till, they met someone who had treatment to remove the cleft, or they attended the awareness camp where they learnt about it.



On response to the question about what had changed after the surgery, it differed on how old the child was when it was operated on. If it was 6-month-old baby, the most prominent response was that he/she was able to eat properly. For a slightly older child, being

able to speak was added benefit apart from being able to eat everything. So, each was an added benefit such as looking better (like a normal child), being able to go to school (not being ashamed, not facing teasing by other children, etc.), having better job opportunities and so on.

- The prominent reaction of the beneficiaries interviewed in various centres was a feeling of relief on learning that the treatment is available and that too free of cost. All of them said that they did not have to spend any money for the treatment or the services.
- They also received medicines and equipment such as special feeding bottles. All of them said they were happy with the services and would recommend the doctor/hospital to anyone they encountered who needed similar treatments.

#### **D. Competent Implementing partners**

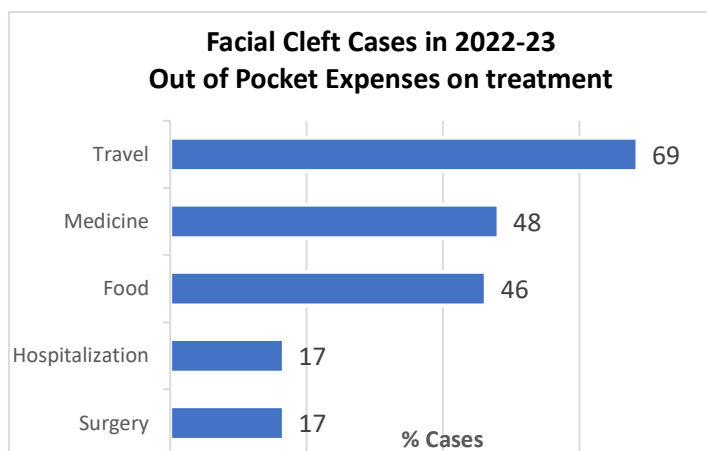
The partner agency ABMSSS is experienced and trusted, which made it possible to expand in newer geographies. *ABMSS, a credible and trustworthy brand.* ABMSS is found to be,

- Legally compliant and an ‘ethically led organization’.
- Consistent with PSL’s values, development approaches, and CSR Foci.
- Immaculate and up to date in data base management; and makes any information about patients available on request, at any time.
- Diligent in using funds and wastages are avoided, having streamlined funding services.
- Has good connect with the hospitals as well as patients and trusted by them all.
- *A Mother Organization extending comprehensive* support to all the centres, periodical reviews, discuss challenges, issues, and solutions.
- Technically updated and a ‘learning’ organization, analyse and learn from their own data, which is significant in depth and proportion.
- Aspires to spread nation-wide - successful in getting international funds for geographies where it is difficult to get CSR partners.

## E. Efficient Funds Utilization

### *The treatment was free of cost...*

Since the treatment was free of cost, most of the patient families did not enquire about how much was the actual cost of the surgery, including other treatments and who was supporting all these services. 81% of the beneficiaries had no idea about the actual cost of the treatment, and 72% were not aware on who gave the financial support.



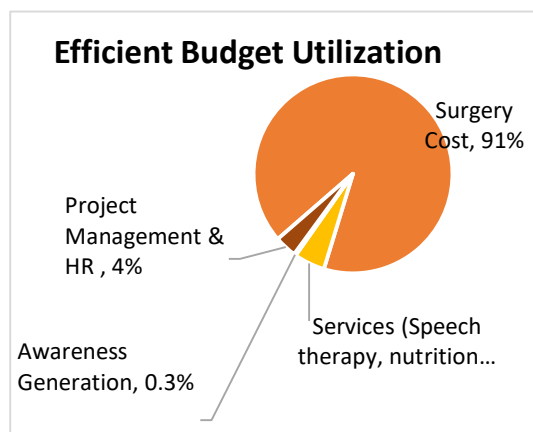
Some of the beneficiaries had to incur some expenditure on travel, food, medicine and other things. Some even said they had to pay for surgery and hospitalization.

72% of the beneficiaries' had excellent opinion about the facilities and expertise of the

doctor and hospital. 22% were happy with it and felt it was good. 83% said that they would recommend the doctor and the agency to others who were in need for similar treatment.

### *More than 90 paise in a rupee going to direct beneficiaries....*

The budget analysis shows that 91% is spent on direct support for the surgeries. 5% is spent on the peripheral services in support of the surgeries which are required for full recovery of the patients. Less than 5% is spent on the project HR and management cost. This indeed is a cost-effective delivery of such proficient service, according to private surgeons interviewed.



Centre	Cumulative Expenditure		No. of patients		Unit cost (Rs)	
	FY 2022	FY 2023	FY 2022	FY 2023	FY 2022	FY 2023
Bengaluru	2,667,500	5,555,000	94	202	28378	27500
Hyderabad	8,231,350	9,649,900	257	320	32029	30156
Nagpur	3,135,000	3,290,500	89	93	35225	35382
Aurangabad, Pune, Pandharpur	5,362,500	6,736,100	184	221	29144	30480

The unit costs for Bengaluru and Hyderabad have gone down slightly and for Maharashtra (except Nagpur) they have gone up slightly. This may be due to introduction of peripheral services in this area which were not available before. Like in 2022, this year too, the unit cost is highest in Nagpur and lowest in Bengaluru.

#### 4. CONCLUSION & RECCOMENDATIONS

It is a comprehensive program with end-to-end services for a very specific health issue of Facial Clefts Deformity. Few other organizations are attending to it. The approach is of saturation, that is to cover patients as many patients as possible, until no more are left. In the areas where the programme is run almost all the existing and treatable patients are covered. No stone is left unturned in finding whereabouts of possible cases. This is a great achievement. As a result, there is increasing awareness that it is a treatable deformity.

The impact assessment has made it clear that there is great satisfaction among the beneficiaries. They have reported it as a life changing benefit. The services provided are effective as well as efficient. The implementation can be certified as no less than ideal. *The scores on Chhaaya Assessment Framework are given in the next section.*

#### Significant Outcomes in Nutshell

- *ABMSS is a credible, technically strong and committed partner,*

- *The program has increasing and significant outreach and become largely beneficial to socially and economically disadvantaged sections of society.*
- *There is an Increasing awareness and access to treatment.*
- *Early detection efforts have been fruitful for complete recovery.*
- *Comprehensive services (such as nutrition, speech therapy, counselling, dental treatment) help in treatment compliance and quality recovery*
- *Excellent documentation, extensive database available of all the patients.*
- *Funds utilization has been diligent and cost effective.*

## **Recommendations**

As little is known about facial cleft and treatment for complete recovery, this CSR initiative of PSL deserves more publicity. It is needed for both creating awareness and promotion of available services. The scientific causes are neither fully known nor possible to fully eradicate, the need for this programme will continue. As a unique initiative under CSR, PSL should not only continue this programme, but also consider expanding to more geographical areas.

- Since outreach is increasing considerably and the partner is stable with pan-India presence, outreach targets can be taken at state level. ABMSSS will have data as to how many cases are detected in the state. Next year, a specific percentage can be decided as outreach target by mutual consultation between PSL and ABMSS.
- From the interviews of the direct beneficiaries and from the analysis of the primary data collected, there is still tremendous scope for creating awareness - particularly preventive awareness - on why such deformities occur and what can be done to avoid them. PSL can invite a specific awareness plan from the partner with specific activities and expected results.
- PSL could consider initiating research on the results of the program. Comprehensive data is already available. The Centres keep in touch with the patients. It would give substantial assessment about the program on which PSL has been spending lot of funds since last few years.

- There are other organizations which are involved in similar programs such as ABMSSS. A comparative analysis will help PSL to know what their outreach is compared to others.
- Some recommendations were given in last year's assessment. Out of those which were not taken up for implementation, still stand valid. PSL can choose some of those for next year's planning. These are repeated below.
  - i) Explore possibility of roping in insurance companies for inclusion of cleft in their products.
  - ii) Reach out to more boundary partners in addition to primary stakeholders to make the programs sustainable.
  - iii) Innovative ideas for supporting employability of the adult beneficiaries or parents of the minor beneficiaries. Such as microfinance for small businesses may be explored.
  - iv) Capacity building of extension workers by preparing a booklet with all requisite information that needs to be shared with the community.
  - v) Supporting Extension workers by building their capacities to reach out at least 2-3 boundary partners.
  - vi) Increasing digital Outreach by identifying key words for search engines in different languages for preventive information sharing.
  - vii) Similar effort can be made to spread awareness in schools where such patients are enrolled.





## 5. IMPACT ASSESSMENT FRAMEWORK FOR FACIAL CLEFT PROGRAM:

Parameters	Relevance of the issue being addressed from the point of view of					Total
Aspects	Beneficiary Community	The CSR mandate	Implementing partners	Development sector	Business footprint	
Chhaaya	1	1	1	0.5	0	3.5
	Most relevant	Child health	Solely dedicated to the cause	Concerns a small minority	Not directly related	
Parameters	Adequacy of Project outreach to demonstrate impact					
Aspects	Absolute outreach	Extent of coverage of affected populations	Inclusion of key stakeholders	Various aspects of the issue addressed	Variety of interventions	
Chhaaya	1	1	1	1	1	5
	Covers all the selected	Saturation approach	Families, doctors, govt functionaries	All aspects addressed	Comprehensive model	
Parameters	Efficiency in resource Use / project design					
Aspects	Cost Consciousness	Mobilization of external resources	Percolation to the beneficiaries	% Overhead costs	Outreach in similar budget projects	
Chhaaya	1	.5	1	1	1	4.5
Parameters	Effectiveness in changing situations					
Aspects	Beneficiary satisfaction	Achieving defined Objectives	Impact compared to similar Projects	Removal of problems symptoms	Addresses root causes of the problems	
Chhaaya	1	1	1	1	0	4
Parameters	Sustainability of project processes and outcomes					
Aspects	Reflected in robustness of the design	Prospects of continuity beyond the project	Sustainability of impacts	Adaptation (of intervention, process)	Institutiona- lization	
Chhaaya	.5	.5	1	1	.5	3.5
Parameters	PSL's mandate (impact, visibility, employee engagement)					
Aspects	Visibility of the organisation	Neglected issue	Employee volunteering	External Recognition	Collaboration (for scale up)	
Chhaaya	1	1	1	0.5	.5	4
<b>Total Score</b>						<b>24.5</b>