



SOLUTIONS GROUP 1

# **EFFECTIVE COMMUNITY- BASED COMPREHENSIVE CLEFT CARE (CCC) INTERVENTIONS**

S4CCC Guideline Series 2025 //

Inclusive Approaches, Lasting Change



# CONTEXT

## **What do we mean by “Community-based Interventions?”**

Community-based interventions prioritize local access – especially for families that live far from a cleft centre. Collaboration with community health providers to deliver appropriate care closer to patients' homes and minimizing the risks and disruption of travel for treatment are core concerns. Telehealth solutions can also play a role in enhancing the reach and efficacy of patient care.

## **Why are Community-based Interventions important within Comprehensive Cleft Care?**

In a cleft service focused mainly on surgery, travel for treatment is an important, but time-limited challenge. CCC involves touchpoints over many years as patients complete multidisciplinary care plans. The additional livelihood and familial burden of ongoing travel for rural families is an important consideration for CCC teams to address.

## **How did we develop these recommendations?**

A diverse group of 10 cleft professionals participated in a 3-month research ‘sprint’ that included a global survey that was completed by 100 cleft professionals from 31 countries. The recommendations which follow were presented and discussed at the March 2025 S4CCC Conference.

“

**“Burden of care is the economic, social and cultural impact that parents/families of a child with cleft have to cope with to seek and meet requirements for comprehensive cleft care over time”**

Speech Professional, India

”



# #1

## RECOMMENDATION #1

# Integrate Centre-based Care with Existing Community Health Programs

To improve CCC outcomes a care pathway should be designed that integrates with existing community health programs or stimulates the creation of new local care options. This will reduce the number of required hospital visits, brings services closer to patients' homes, and increases treatment adherence. Partnering with local governments and not-for-profits will avoid duplication of services and augments the sustainability of CCC.

## Rationale

# 100%

of respondents indicated that providing CCC services closer to where patients live would be beneficial, with 48% of LMIC respondents indicating that this is already feasible.

# 45%

of respondents reported that most of their patients must travel 3+ hours to reach the nearest CCC centre

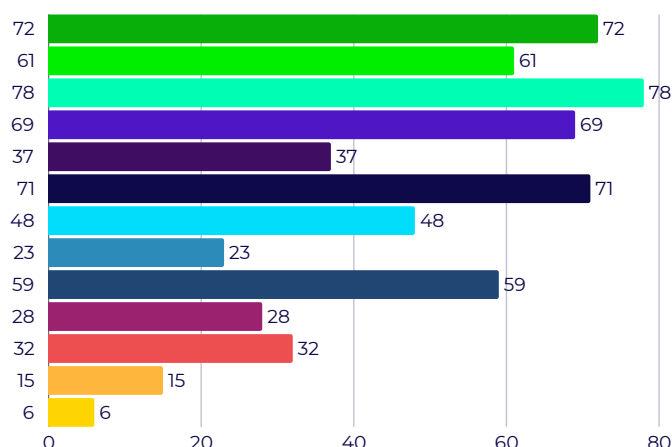
# 78%

of respondents point to one or more components of CCC that could be effectively delivered in a community-based setting, including: newborn examination for home-births (61 respondents); feeding and nutrition (78); early language stimulation (71); and psychosocial support (69).

Which components of CCC do you believe can be most effectively moved to a community-based setting instead of a tertiary hospital?

n=100

- Pre-natal counselling
- Newborn examination for home births
- Feeding, nutrition counselling and growth monitoring
- Psychosocial support
- Post-operative care for wound healing and scar management
- Counselling for early language stimulation and development
- Speech therapy post-surgery
- Screening for VPD
- Dental and oral hygiene
- Orthodontic monitoring and adjustments
- Hearing and ENT care
- Surgical Care
- Other



# #2

## RECOMMENDATION #2

# Establish Financial and Logistical Support for Community-based Care

While ultimately cost-efficient, launching community-based care requires additional investment. By exploring sustainable funding models, diversifying funding sources, and negotiating new partnerships, more equitable access to care for patients irrespective of their socioeconomic status or rurality can be achieved.

## Rationale

89

respondents ranked 'sufficient financial resources' as a critical requirement for community-based care.

93

respondents noted that dedicated funding for community-based care would be a crucial asset. Supporting patient transportation costs and equipment for outreach initiatives also figure prominently in a successful community-based care model.

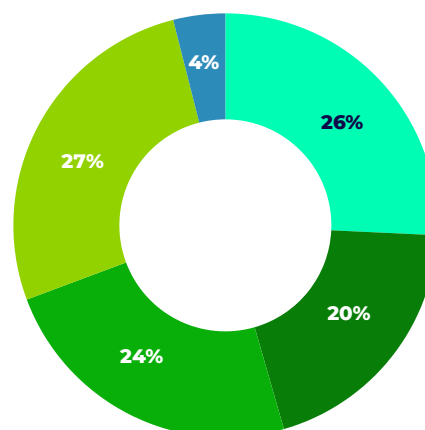
## Constraints to Consider

- Procuring a space in which to provide local care
- Crafting agreements where multiple local service providers exist
- Securing funding for infrastructure and recurring expenses can be a challenge

Which of these elements are crucial to be in place for a cleft team to facilitate community-based services in cleft care?

● Sufficient financial resources	89
● Sufficient infrastructure, such as buildings and facilities	79
● A skilled and experienced cleft team	84
● Training in developing and implementing a community-based care model	93
● Other	14

n=100



# #3

## RECOMMENDATION #3

# Implement Hybrid Care Models

A Hybrid Model is a blended approach to cleft care that combines both in-person and remote (telehealth/virtual) services to deliver multidisciplinary cleft care—especially in resource-limited or geographically dispersed settings. Task-shifting, whereby specific CCC tasks are delegated to health workers with fewer qualifications, can be a helpful strategy within hybrid care.

### Rationale

Integrating community outreach and telehealth strategies into a CCC framework can help address patient barriers and enhance timely follow up, thereby improving access to care. Hybrid care models can also help to reduce the burden of travel and costs for families, making healthcare more accessible and efficient. It should be noted that many LMIC contexts do not have equitable access to the technology that facilitates virtual service provision.

66%

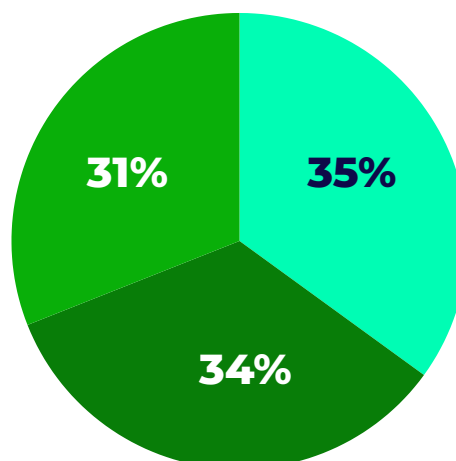
of LMIC respondents report employing some degree of telehealth

Task Shifting requires careful planning, training and adequate supervision

Does your centre currently use telehealth/  
mobile technology to help deliver care?

- Yes
- No
- In a limited way

n=100



# #4

## RECOMMENDATION #4

### Develop Comprehensive Caregiver Training

Targeted support for family members can play a pivotal role in improving outcomes for patients. When caregivers are equipped with knowledge and skills, the ripple effects on a child's health and well-being are profound. Comprehensive caregiver training is especially powerful where health systems are under-resourced. With proper training, caregivers can:

- Extend the reach of cleft specialists
- Act as frontline health advocates in the community
- Foster peer support networks

#### Rationale

Empowering caregivers to navigate their child's cleft care plan can address caregiver burden and stress, and lead to better patient outcomes. Introducing the following shared decision-making principles and effective feedback systems for caregivers, supports patient adherence to agreed-upon treatment plans:

#### Open Dialogue

→ family input is solicited, and patient preferences are respected whenever possible

#### Consistent Support

→ families remain in touch with the CCC team

#### Access to Information

→ families are provided with timely, personalized resources

“



**"Providing parents with precise information regarding the whole treatment process with all its aspects, a kind of an action plan and referrals to the trusted health care specialists can reduce the burden of care."**

- Cleft Care Coordinator, Bulgaria

”

# #5

## RECOMMENDATION #5

# Establish comprehensive monitoring and evaluation indicators

Comprehensive monitoring and evaluation (M&E) indicators transform cleft care from a collection of good intentions into a **measurable, accountable, and continually improving system**. Indicators allow teams to discern the impact of both centre and community-based initiatives, making changes in delivery based on evidence.

### Rationale

Clear program evaluation measures allow CCC teams to evaluate progress and enhance accountability to patients, funders and administrators. These should include clinical and functional outcomes; accessibility and continuity of care metrics; and assessment of a patient and family's overall well-being. The following sequence can be helpful:



- Develop assessment protocols and data collection tools
- Use an effective data management system/tools/strategy
- Establish program evaluation time points
- Monitoring and evaluation indicators allow clinical and functional outcomes to be monitored, accessibility and continuity of care to be measured, and the patient and family's overall well-being to be considered.

“

**“If indicators are met, it suggests comprehensive cleft care is being effectively delivered in the community. If gaps exist, interventions like training programs, financial support, awareness campaigns, and better referral systems may be needed.”**

- Speech Professional, Ghana



”



## CONCLUDING THOUGHTS:

Children born with facial clefts need multiple surgical procedures and other interventions. If the burden of care can be reduced by adopting these recommendations without compromising final outcomes, this is in the best interest of the patients and their families.

Doing so in a considered and coordinated fashion may reduce overall health expenditure by improving the efficiency of service provision.

## AUTHORS:

### Co-Chairs

Prof. B. Subramaniyan, Speech Therapy, India  
Dr. David Gillett, Surgery, Australia

### Members

Dr. Felicity Mehendale, Surgery, United Kingdom  
Dr. Marina Campodonico Frisch, Paediatric Dentistry, Chile  
Dr. Getaw Gebeyehu, Surgery, Ethiopia  
Dr. Savitha Vadakkanthara Hariharan, Speech, India  
Chrystelle Hanitriniaina, Anesthesiology, Madagascar  
Dr. Pumulo Maimbolwa, Medical Doctor / Paediatrics, Zambia  
Phanomwan Yoodee, Social Work, Thailand  
Dr. Andrea Domínguez Rivera, Orthodontics, Mexico

### Host

Danaka Robertson, NGO, Canada

## RESOURCES:

Click to access the following

- [Roundtable Video](#)
- [Kantar, R., et al. \(2021\). Comprehensive Cleft Care Delivery in Developing Countries: Impact of Geographic and Demographic Factors. Journal of Craniofacial Surgery. Publish Ahead of Print. 10.1097/SCS.00000000000007624.](#)
- [Murthy, J. \(2019\). Burden of Care: Management of Cleft Lip and Palate. Indian Journal of Plastic Surgery. 52. 10.1055/s-0039-3402353.](#)

