



SOLUTIONS GROUP 3

MAKING THE CASE FOR CORE CCC DISCIPLINES

S4CCC Guideline Series 2025 //

Inclusive Approaches, Lasting Change



CONTEXT

What do we mean by “Core Comprehensive Cleft Care (CCC) Disciplines?”

Cleft conditions affect multiple aspects of a person’s health requiring a **team approach** to treatment. Core CCC disciplines refer to the multidisciplinary team of specialists involved in the treatment and rehabilitation of individuals with cleft lip and/or palate.

Why is pursuing year-round CCC important?

- To ensure that treatment and rehabilitation approaches can address **short- and long-term** needs of all patients with cleft conditions.
- To manage patients who are **presenting late**, also for those with **complex conditions and comorbidities**.
- Year-round CCC also requires:
 - Building capacity and sustainability, bridging training gaps and necessary expertise to establish or support local multidisciplinary cleft care teams.
 - Engaging with patients, caregivers and communities to increase awareness, and prioritization of CCC.

How did we develop these recommendations?

A diverse group of 12 cleft professionals participated in a 3-month research ‘sprint’. This included a global survey completed by 90 cleft professionals from 23 countries. The recommendations from this exercise were presented and discussed at the March 2025 S4CCC Conference.

“

“Year-round Comprehensive Cleft Care (CCC) ensures consistent access to necessary treatments and follow-up services, improving patient outcomes and reducing the risk of complications”

— Speech Professional, Ethiopia.

”



#1

RECOMMENDATION #1

Develop context-specific Standard Operating Procedures (SOPs) for the CCC team and for each clinician within an institution/system.

Rationale

Respondents identified improved treatment outcomes as a key benefit of year-round CCC. SOPs for the CCC team and for each specialist within an institution/system enable a patient-centered, team-based, and systems-focused approach to care.

Specialty and team-based SOPs enhance interdisciplinary care, while institutional SOPs ensure that teams maximize health system benefits for patients. This ensures that activities such as detection, referral, patient intake and orientation, care delivery, and support mechanisms are responsive to patients throughout their care journey.



“...Year- round care allows for early identification and prevention (if possible) of potential issues. Families benefit from a more predictable care schedule. When they’ve met with all of the specialists within the team, it reduces uncertainty and stress for them.”

— Psychology Professional, Bulgaria



#2

RECOMMENDATION #2

Set up quality assurance protocols and guidelines rooted in patient outcomes

Rationale

Standard patient care protocols and guidelines allow outcomes to be assessed and support better outcomes.

A patient-first approach requires evaluation of quality assurance metrics that begin with the patient, continue with the team, and include systemic components. Patient-focused care includes metrics related to the impact of health delivery activities in surgery, speech and hearing, oral health, psychosocial status, and others. Team metrics could include satisfaction, efficiency, quality, and outcomes of care delivered.

A systems quality check may include efficiency of investments and the ability to respond to patient societal needs in areas such as accessibility, availability, affordability and acceptability.



“Providing year-round follow-up allows growth monitoring, ensuring the best health conditions and detecting possible complications before and after lip and palate closure surgeries, as well as supporting families to understand the importance of adherence to treatment after the first year of life”

— Speech Professional, Mexico



#3

RECOMMENDATION #3

Identify and address barriers to accessing coordinated CCC including transportation, distance, ease of access, and affordability

Rationale

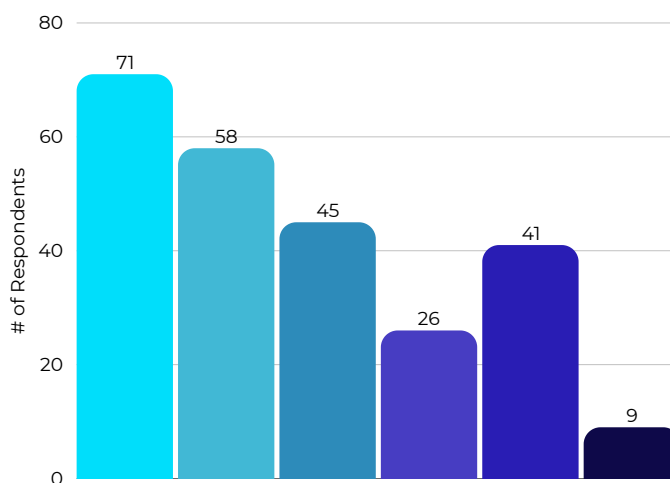
Increasing access to strong, coordinated CCC translates into a higher patient population interested in services. More people, therefore, can obtain the required treatment.

Cultural, geographical and financial barriers limit access to CCC and stifle opportunities for treatment and rehabilitation. A **patient-centered approach** requires understanding the factors stifling patient demand. It also needs to decipher variables that increase the number of patients unable to get care or abandoning care.

Understanding these barriers can support CCC teams in developing resilient systems that enable patients to better access CCC. These systems can take many forms such as tie-ups with local **transportation** companies to facilitate transport or connections with **accommodation** near the hospital at a bulk rate.

What do you believe are the top 3 challenges faced by patients with cleft conditions in accessing care in your context?

- Access (distance, transportation)
- Availability (no care or limited CCC available)
- Affordability (care is expensive or impoverishing)
- Acceptability (quality and safety related challenges)
- Cultural (beliefs influencing cleft care)
- Other



#4

RECOMMENDATION #4

Collaborate with hospital administration to identify funding opportunities for CCC

Rationale

To establish a sustainable year-round service which is integrated with the existing health care system, cleft professionals may also invest time and knowledge in **non-clinical areas** driving prioritization within institutions and systems; and supporting greater inclusion of CCC.

Societal inclusion of patients with cleft conditions requires experts to use their knowledge and engage beyond surgical wards or consultation rooms, educating leaders, communities, and potential supporters of CCC. Governments, civil society, academics and the private sector are potential partners in expanding and supporting access to CCC through sustainable funding mechanisms.



“

“Without hospital commitment...[seeking] external grants or donations may not be sustainable.”

— Oral Health Professional, India

”



#5

RECOMMENDATION #5

Advocate with families, communities, and clinicians about the importance of CCC in achieving good patient outcomes.

Rationale

The connection between CCC and good patient outcomes, including community inclusion, is not yet well understood in many contexts.

Patients and families have powerful voices and an important role to play in advocating for CCC. When the perspectives of caregivers and supporters are broadly aligned with those of CCC Team members, decision makers and funders take note. Patients and families are effective advocates for care that is accessible, available, of good quality, affordable, and supportive of patients' full inclusion in society.

Advocacy efforts have driven systems to become more responsive in the case of other conditions. Lessons in global health show that awareness of needs can lead to higher prioritization. Such strategies can be used by patients, providers, and partners to advance organization, resourcing, improvements, and prioritization of CCC.



“Comprehensive cleft care will allow the patients to get optimal care and access to treatments. Thereby meeting the patient's overall health needs.”

— Speech professional, Nigeria



CONCLUDING THOUGHTS:

As CCC becomes more globally prevalent, advocacy for the core disciplines and resources needed for its implementation must continue to grow. Use these guidelines as a starting point of discussion with your hospital administration, health departments, patients, and clinicians, to make the case for the integration of CCC into broader treatment plans integral to health systems.

The data that shaped our recommendations included strong representation from West Africa. Adapting this work in light of your own local context is essential. We offer these guidelines to serve as inspiration for CCC teams worldwide.

AUTHORS:

Co-Chairs

Dr. Ruben Ayala, NGO Leader, United States
Dr. Omolola Orenuga, Paediatric Dentistry, Nigeria

Members

Dr. Mekonen Eshete, Surgery, Ethiopia
Maan Sukte, Speech, Myanmar
Dr. Mohammed A.S. Abdullahi, Surgery, Nigeria
Adam Mang'ombe, Speech, Tanzania
Sarah Kilcoyne, Speech, United Kingdom
Dr. Anne Hing, Medical Doctor/Paediatrics, United States
Kylie DeBoer, Research, United States
Prof. Vignesh Kailasam, Orthodontics, India
Dr. Teshome Assefa, Anesthesiology, Ethiopia
Daniela Garcia, Management/Coordination, Mexico

Host

Andrew Inglis, NGO, Canada

RESOURCES:

Click to access the following:

- [Roundtable Video](#)
- [Jumbam, D. T. \(2020\). How \(not\) to write about global health. BMJ Global Health, 5\(7\), e003164. <https://doi.org/10.1136/bmjgh-2020-003164>](#)
- [Jumbam, D. T., Kanmounye, U. S., Alayande, B., Bekele, A., Maswime, S., Makasa, E. M. M., Park, K. B., Ayala, R., Onajin-Obembe, B., Samad, L., Roy, N., & Chu, K. \(2022\). Voices beyond the Operating Room: centring global surgery advocacy at the grassroots. BMJ Global Health, 7\(3\), e008969. <https://doi.org/10.1136/bmjgh-2022-008969>](#)
- [Mohammed, H. \(2022, November 9\). Oral Health Advocacy Initiative: Tackling Cleft Lip in Rural Communities through Surgery and Advocacy. Nigeria Health Watch. <https://articles.nigeriahealthwatch.com/oral-health-advocacy-initiative-tackling-cleft-lip-in-rural-communities-through-surgery-and-advocacy/>](#)