Circle of Cleft Professionals

SOLUTIONS GROUP 1

EFFECTIVE COMMUNITY-BASED COMPREHENSIVE CLEFT CARE (CCC) INTERVENTIONS

S4CCC Guideline Series 2025 //

Inclusive Approaches, Lasting Change

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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%

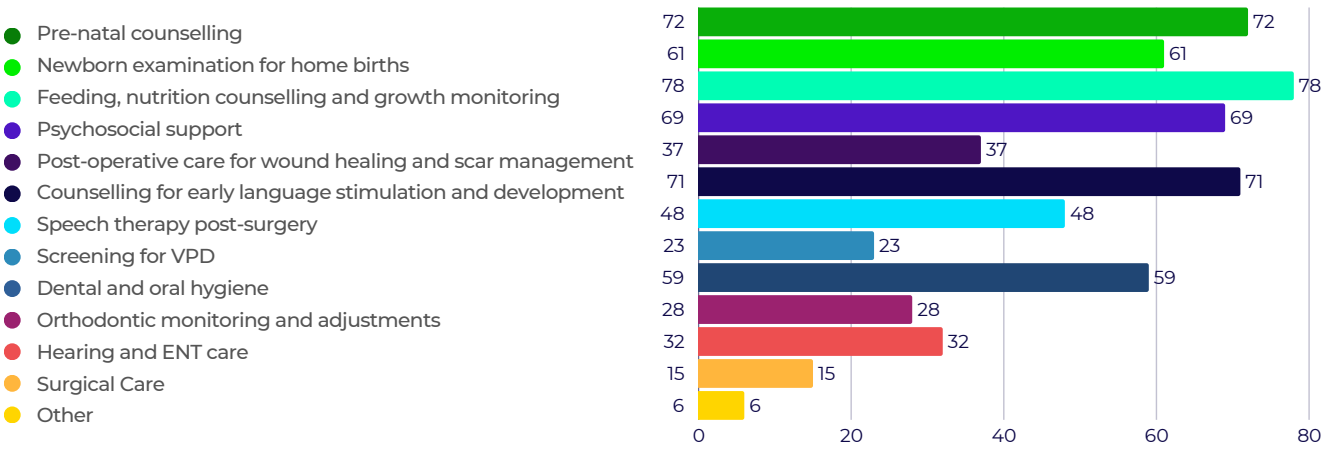
of respondents reported that most of their patients must travel 3+ hours to reach the nearest CCC centre

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



#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.

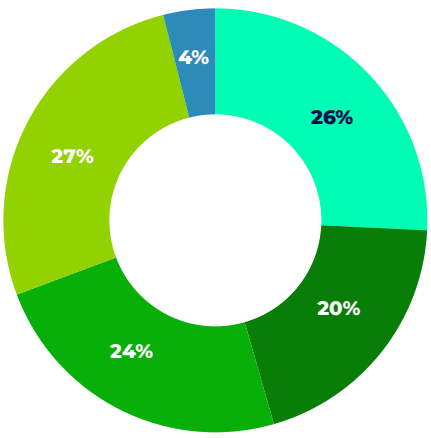
Constraints to Consider

- 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.

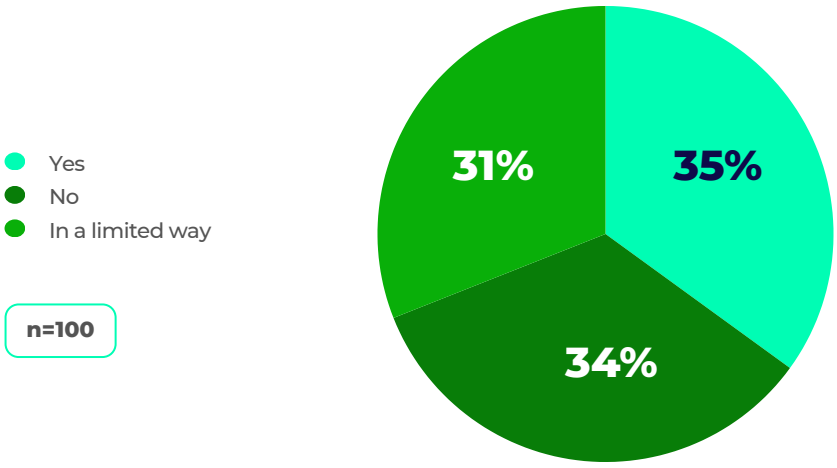
Rationale

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?



#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

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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.

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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.0000000000007624.
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SOLUTIONS GROUP 2

MULTIDISCIPLINARY CCC TEAM-BUILDING

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CONTEXT

What Do We Mean by "Multidisciplinary CCC Team-Building"?

Comprehensive Cleft Care (CCC) depends on the **coordinated efforts** of **diverse health professionals**—such as speech therapists, surgeons, anesthesiologists, orthodontists, pediatricians, nutritionists, nurses, and psychologists. Team-building refers to the process through which these professionals **learn to collaborate** effectively to **improve patient outcomes.**

Why Is Team-Building Important?

When cleft professionals work well as a team:

- Patient-centred care improves
- Resources are used more efficiently
- Health systems are strengthened
- Communication within the team and with families is enhanced

Barriers in LMIC Contexts Include:

- Lack of dedicated clinical space
- No electronic medical records
- Inadequate compensation for team members
- Shortages of trained specialists (e.g. speech therapists, orthodontists)

How Were These Recommendations Developed?

A diverse group of **10** cleft professionals engaged in a **three-month research sprint**, including a global survey completed by **113** professionals from **34** countries. The resulting recommendations were presented and refined during the **March 2025 S4CCC Conference.**

> **"Being volunteers, sometimes professionals do not have the time to provide comprehensive care."**
>
> Oral Health Professional, Dominican Republic

#1

RECOMMENDATION #1

Toward the development of sustainable and effective delivery of CCC, we must collaborate effectively, plan meticulously, and engage the wider health system.

Essential components include:

a) Compliance with local healthcare regulations
b) Functional and suitable working space
c) Adequate equipment and supplies
d) Means and methods for recruiting, training, and retaining skilled staff
e) Building strong partnerships with community healthcare providers to improve accessibility and ensure continuity of care

Rationale

Advice from Respondents:

- **Build partnerships** and **collaboration** with local hospitals
- Cultivate collaboration, **respect**, and **trust** between team members
- Adhere to **protocols** for effective delivery of service while ensuring equity
- Establish a teamwork dynamic and **internal referral system**
- Coordinate with **government** institutions
- **Remunerate staff** to reinforce team stability and commitment
- Involve **community stakeholders** (e.g. traditional leaders, religious leaders)

"Administrative support is VERY IMPORTANT... so providers can concentrate on patient care and do not have to worry about day-to-day operations, fundraising, marketing, data management, etc."

Orthodontist, Philippines

#2

RECOMMENDATION #2

Identify and address barriers as a team

Multidisciplinary team care in low- and middle-income countries (LMICs) faces numerous challenges, but addressing the following key priorities will improve care:

a) Allocating **dedicated clinic space** for joint patient consultations
b) Appointing a **team leader** with strong leadership abilities
c) Offering adequate **support for providers** to foster retention

Rationale

Cleft care teams often work in **fragmented systems** with **limited resources,** making it essential to identify and address barriers collaboratively. A team-based approach ensures that challenges such as lack of dedicated clinic space, leadership gaps, and provider burnout are tackled holistically rather than in isolation.

Establishing shared clinical space enables coordinated, patient-centered care; appointing a capable team leader strengthens communication and accountability; and supporting providers through training, recognition, and fair compensation helps retain skilled professionals. When teams work together to remove systemic obstacles, they create a more **sustainable, efficient,** and **effective** model for delivering comprehensive cleft care.

"...Referrals between the team's specialties is very important, prioritizing which area is most important in care when starting the patient's treatment and then holding periodic meetings between team members to evaluate cases"

Speech Professional, Argentina

#3

RECOMMENDATION #3

Invest in the skills of the Team Leader

CCC Team Leaders should demonstrate skill in the following areas:

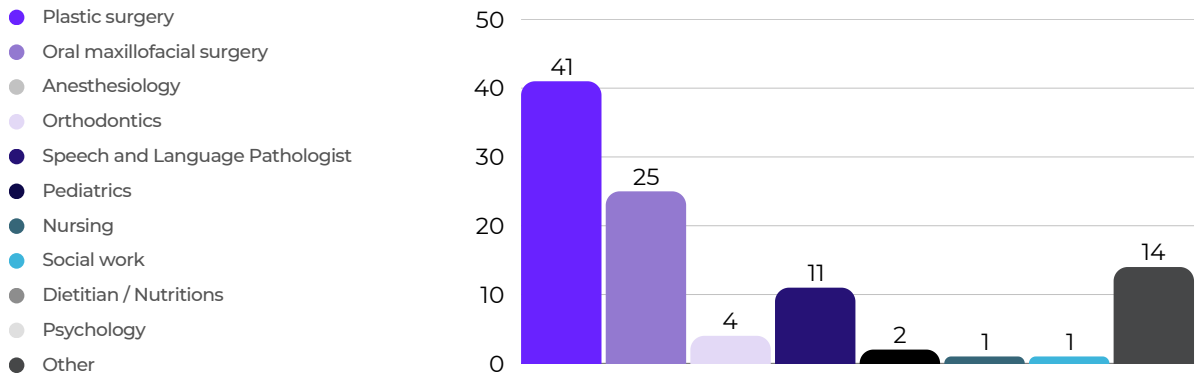
a) Resource management
b) Program planning
c) Team dynamics
d) Advocacy and community engagement

Rationale

Effective leadership is vital to the success of Comprehensive Cleft Care (CCC) programs, particularly in low-resource settings. A CCC leader's clinical competency does not mean that they will have leadership skills to effectively manage a CCC team. Often a CCC leader is chosen based on their discipline (e.g. surgery) or gender, not based on their leadership aptitudes.

Proficiency in resource management ensures that limited supplies, funding, and personnel are used efficiently. Strong program planning skills help structure care delivery across disciplines and over time, ensuring continuity and measurable impact. Understanding team dynamics fosters collaboration, accountability, and morale within multidisciplinary teams. Finally, advocacy and community engagement are essential for raising awareness, reducing stigma, mobilizing support, and connecting families to care. These leadership skills can be fostered through professional development opportunities.

What discipline best matches the discipline of your CCC team leader?



"The surgeon does not necessarily have to be the leader of a team. His or her role is no more important than that of the other specialists on the team."

Speech Professional, Argentina

#4

RECOMMENDATION #4

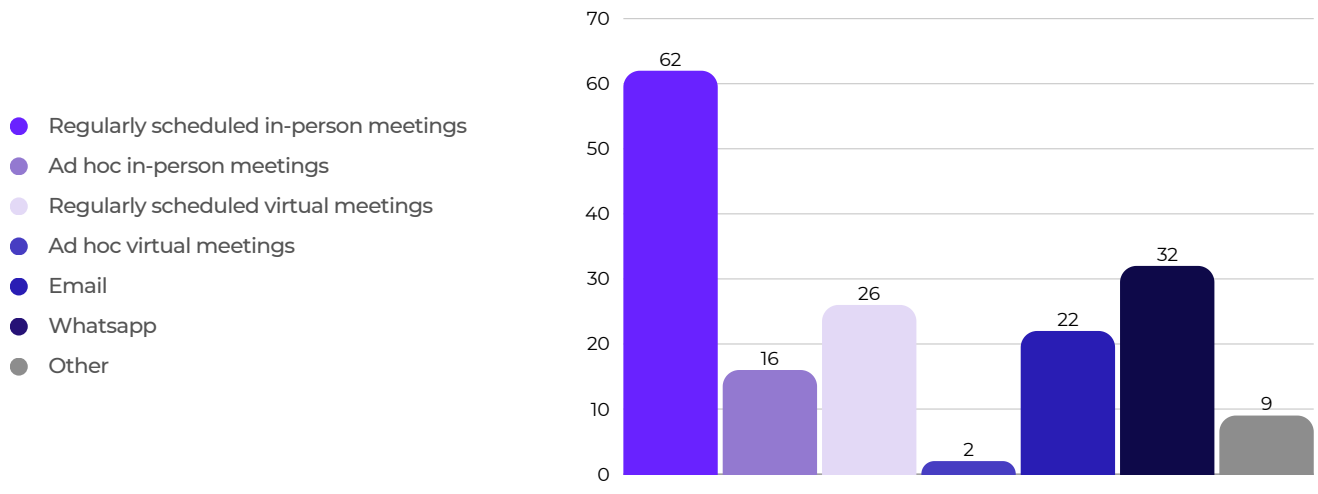
Demonstrate Open Communication and Value Every Perspective

A structured approach to team-building —such as **regular team meetings** and a **dedicated space** for discussion—supports open dialogue and coordinated care. Inclusive teams make better decisions, especially when navigating **complex cases** with limited resources.

Rationale

Comprehensive Cleft Care (CCC) depends on effective collaboration across multiple specialties. When leaders foster open communication and actively seek input from all team members, it promotes true multidisciplinary decision-making—essential for delivering high-quality, patient-centered care.

In LMIC settings, **cultural or institutional hierarchies** may prevent some voices from being heard, but valuing every perspective helps create an inclusive, respectful environment where all feel empowered to contribute. This strengthens team cohesion, improves motivation and retention, and reduces burnout.



#5

RECOMMENDATION #5

Prioritize addressing essential resource gaps for CCC

In LMICs, funding gaps often prevent access to timely surgery, speech therapy, oral health and ongoing care. Building financial partnerships (with NGOs, governments, or private donors) enables CCC teams to serve more patients, sustain services, and reduce out-of-pocket costs for families.

Engaging families, local leaders, and community health workers ensures better follow-up, earlier referrals, and culturally appropriate care. It also strengthens local ownership and long-term sustainability.

Rationale

Starting and maintaining effective CCC teams requires **monetary resources.** It is equally important to build **partnerships** with the community and other stakeholders that guarantee the sustainability of the work.

“...Securing resources to support both hospital and community care, along with establishing patient support networks, will enhance accessibility and provide vital emotional support for families”

Speech professional, Ethiopia

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Concluding Thoughts:

These recommendations are intended to be applied in LMIC contexts – whether a CCC team is just beginning, or the team's work is being deepened. One important element that came up repeatedly is the role of the CCC leader. Currently, there are not many opportunities to develop leadership competencies for this position, yet it has great influence in the success of a team. Skills like Program Management or Communications are currently learned "on the job".

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Resources:

Click to access the following

- Roundtable Video
- Stoller, J. (2021). Building Teams in Health Care. Chest.
- Nancarrow, S. et al. (2013). Human Resources for Health.
- Wei, H., Horns, P., Sears, S., Huang, K., Smith, C. & Wei, T. (2022) A systematic meta-review of systematic reviews about interprofessional collaboration: facilitators, barriers, and outcomes, Journal of Interprofessional Care, 36:5, 735-749, DOI: 10.1080/13561820.2021.1973975

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ABMSS Smile · CLEFT bridging the gap · Deutsche Cleft Kinderhilfe e.V. · European Cleft Organisation · Global Smile Foundation · Noordhoff Craniofacial Foundation · Operation Smile · PROJECT HARAR · SmileTrain · Transforming Cleft · ACPA

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SOLUTIONS GROUP 3

MAKING THE CASE FOR CORE CCC DISCIPLINES

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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

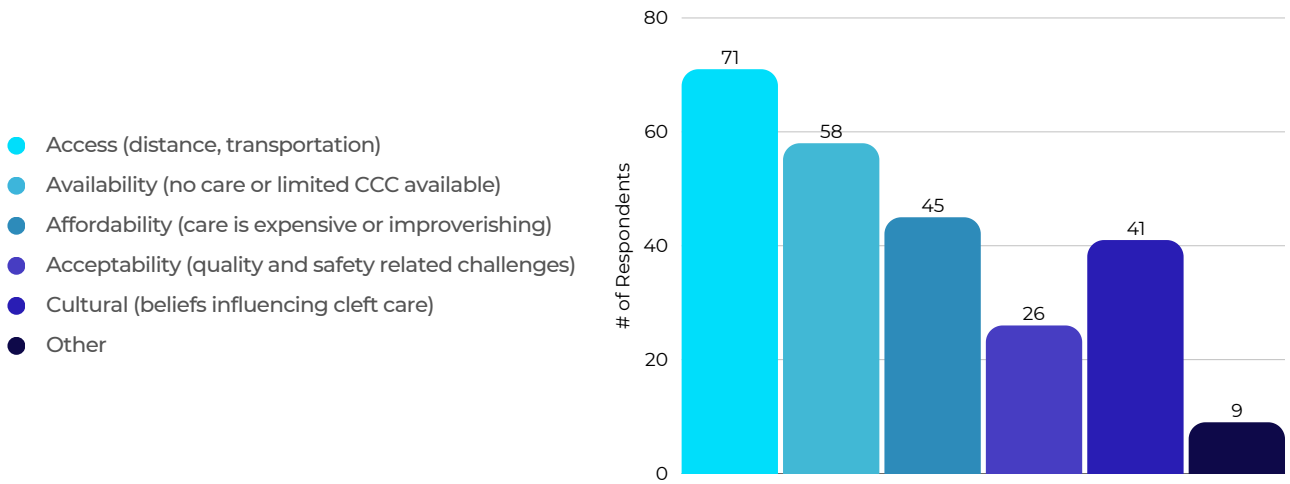
Rationale

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?



#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

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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.

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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/

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SOLUTIONS GROUP 4

SUPPORTING PARENTS IN SHARED DECISION-MAKING

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CONTEXT

What is “Shared Decision-Making”?

Shared decision-making (SDM) is an evidence-based process through which a **clinician facilitates a patient taking ownership of treatment decisions** by integrating clinical expertise with the patient’s preferences, values, and beliefs.

Why is ‘Supporting Parents in CCC Treatment Decision-Making’ important?

Shared decision-making optimizes healthcare by:

- **Increasing patient and family knowledge** of treatment protocols, options and risks
- **Reducing conflict and improving communication** between patients, families, and healthcare providers
- Helping patients and families to **feel more in control** of their care
- **Improving adherence** to evidence-based treatment protocols
- Reducing decisional regret and **increasing treatment satisfaction**
- **Reducing the burden of care** and optimizing the use of limited healthcare resources

How were these recommendations developed?

A diverse **group of 13** cleft professionals participated in a **three-month research ‘sprint’** that included a global survey completed by **162** cleft professionals from **30 countries.** The recommendations which follow were presented and discussed at the **March 2025 S4CCC Conference.**

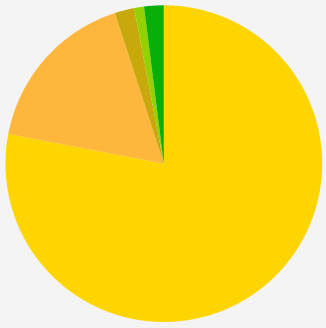
“We should invite challenges and questions from parents and patients to involve them in SDM. It should inform the conversation.”

Speech Professional, UK

95%

of respondents Agree or Strongly Agree that ‘SDM is important for CCC’

Shared decision-making is important for Comprehensive Cleft Care (CCC).



Strongly Agree	**78%**
Agree	**17%**
Neutral	**2%**
Disagree	**1%**
Strongly Disagree	**2%**

#1

RECOMMENDATION #1

Invite family members to participate fully in treatment decision-making

Providing information, phased to match key milestones throughout the CCC treatment pathway and co-creating culturally sensitive decision-aids helps parents understand individual treatment options, benefits, and risks.

Rationale

- Parents and caregivers may not be aware of their potential role in treatment decision-making.

"Patients may defer to healthcare providers and not actively participate in decisions."
/ Speech Professional, Ethiopia

- Cultural norms are a barrier to SDM in many regions.

31% of survey respondents indicated 'Cultural norms' as a barrier to implementing SDM

"Traditionally, there is a cultural tendency to strongly respect the opinions of physicians, and patients and their families are inclined to follow the doctor's recommendations."
/ Speech Professional, Japan

- Literacy and language/dialect differences may also impact the ability to facilitate SDM.

46% of survey respondents indicated 'Patient/family literacy' as a barrier to implementing SDM

- There are a lack of decision-making aids/tools in CCC.

72% of respondents indicated that 'visual aids for patients and families' would be helpful for facilitating SDM

"We have had instances where a male figure disagrees with the [treatment] decision. If he doesn't consent, treatment cannot be given regardless of if the treatment is free."

— Speech Professional, Nigeria

#2

RECOMMENDATION #2

Invite children and young people to participate fully in treatment decision-making

Co-create developmentally appropriate and culturally sensitive resources to help patients understand treatment options, benefits, and risks AND empower them to discuss their needs and preferences with family members and providers.

Rationale

- Children's and young people's needs and preferences may not always be fully considered during the decision-making process. Families and patients may also disagree on the optimal approach to care.

"Sometimes...parents find it hard to allow the child to be as involved in the decision-making process as we would like".
/ Psychologist, England

"[A challenge is] understanding the complexities of SDM in families and taking into account multiple perspectives".
/ Psychologist, Wales

- There are a lack of decision-making aids/tools in CCC.

25% of respondents indicated 'Lack of decision-making aids/tools' as a barrier to implementing SDM

79% of respondents indicated that 'information guides/videos for patients and families' would be helpful for facilitating SDM

"Treating teams take pride in aesthetics and appearance. We wait for the perfect visual presentation and completely undermine the satisfaction of the patient and what they feel. This attitude has to change."

— Speech Professional, India

#3

RECOMMENDATION #3

Sensitize healthcare providers to the benefits of shared decision-making

Co-develop a culturally sensitive training package for healthcare providers addressing common concerns and challenges.

Rationale

70% of respondents indicated that 'shared decision-making resources for health providers' would be helpful in facilitating SDM

- While most respondents felt SDM was important, there was an indication this view is not held by all healthcare providers.

15% of respondents indicated 'provider belief that SDM is unimportant/ineffective' as a barrier to implementing SDM

"[A barrier is] the common belief that the less patients know, the better."
/ Psychology Professional, Nigeria

- Many respondents felt they did not have enough influence or involvement in their patients' treatment to facilitate SDM.

30% of respondents indicated 'Individual health providers do not have enough influence or involvement in the patient's overall treatment' as a barrier to implementing SDM

"[A barrier] is the belief that only the surgeon should have a say in all the treatment."
/ Speech Professional, Romania

"We surgeons are at the top of the hierarchy, yet we are the least trained to spend time talking to patients and families."

— Surgeon, Spain

#4

RECOMMENDATION #4

Equip healthcare providers with the skills to facilitate shared decision-making

Co-develop culturally sensitive resources that guide healthcare providers through the process.

Rationale

Respondents expressed concern about healthcare providers' familiarity with SDM principles and how successful they/their team are at demonstrating SDM practices.

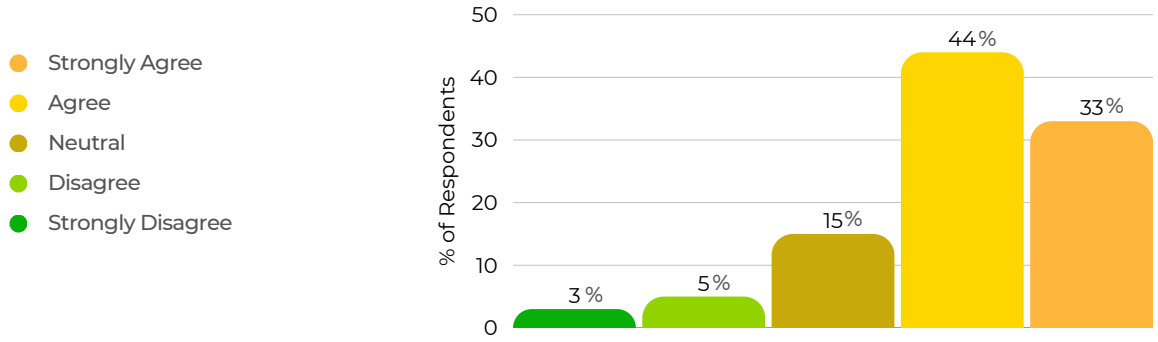
27%

of respondents indicated 'healthcare provider knowledge of SDM principles' as a barrier to implementing SDM

Only 33%

of respondents Strongly Agree that '[their] team successfully demonstrates SDM practices'

My team successfully demonstrates shared decision-making practices



"It is very beneficial when surgeons have worked with a psychologist on how to encourage SDM because they are perceived by the parents as the most authoritative figure within the team."

— Psychologist, Bulgaria

#5

RECOMMENDATION #5

Ensure patient and parent perspectives are included in future work

Gather data about SDM perceptions and practices from patients and parents/caregivers in low- and middle-income countries (LMICs)

Rationale

This survey only elicited the views of healthcare providers. Additional recommendations may be made with data from patients and parents/caregivers.

The topic of **cultural considerations** was prominent throughout survey respondents' comments. Further examination into this area is recommended, as cultural norms and expectations can both facilitate and be a barrier to implementing SDM, particularly in LMICs. It is important to consider local context when examining best practices in educating patients, families, and healthcare providers about SDM.

> **"Parent education on CCC and SDM should be part of treatment, not just an option - same as pediatrics, dentistry, or any other treatment. This is the most important step to take before even treating the patient, by giving equal time and importance as surgery to educate the parent first."**
>
> — Surgeon, Madagascar

Circle of Cleft Professionals

CONCLUDING THOUGHTS:

Shared decision-making is a relatively unexplored topic in the context of CCC, and particularly so in LMIC contexts. Healthcare providers are encouraged to consider these guideline recommendations to inform how shared decision-making could be applied or improved in their local context. Given that the development of these guidelines only included the views of healthcare providers, seeking further data around the patient and family perspective is a crucial next step. Ultimately, this work encourages cleft professionals to collaborate on the co-development of training materials and resources to facilitate shared decision-making and ensure best practice for patients with clefts around the world.

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RESOURCES:

Click to access the following

- Roundtable Video
- Gao, C., Waddell, K., Wilson, M. (2018). Rapid Synthesis: Supporting Parents in Making Informed Decisions in Relation to their Children's Health Needs. McMaster Health Forum.
- CoCP Webinar: Shared Decision-making in Cleft and Craniofacial Care

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