

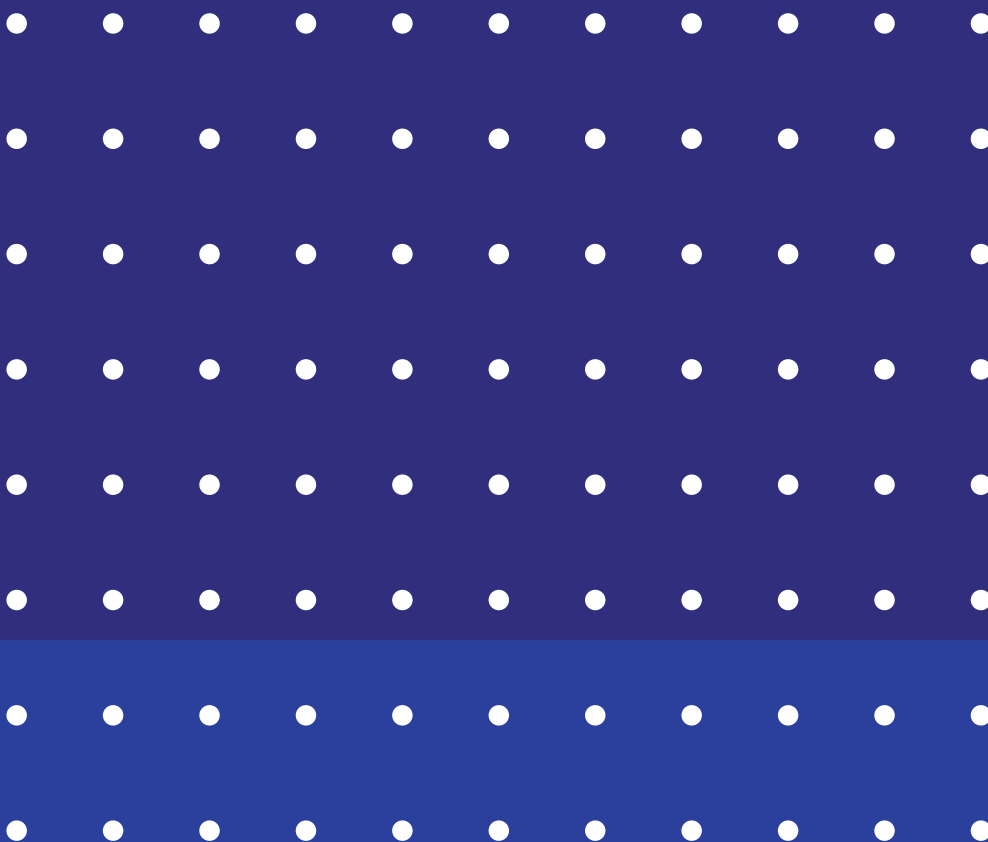
# Solutions4CCC

COVID & Beyond



Findings and  
Recommendations  
for moving forward  
with Comprehensive  
Cleft Care in Low  
and Middle Income  
Countries

June, 2021



circle  
of cleft professionals



## FOREWORD

Constraints spur innovation. Beyond the often heart-rending impact of COVID-19 in Low and Middle Income Country (LMIC) contexts, cleft professionals have discovered and adapted to new ways of supporting families in overcoming the limitations of cleft lip and palate.

For this second edition of the [Solutions for Comprehensive Cleft Care \(S4CCC\)](#) conference, the [Circle of Cleft Professionals \(CoCP\)](#) invited 40+ global cleft leaders to an intensive 2+ month experience of virtual collaboration: across regions, languages, disciplines, and NGO affiliations. These colleagues are to be commended for piloting a [novel approach](#) to global taskforce work.

Building upon the findings of the CoCP's recent [global survey of CCC professionals](#), these 6-8 person Solutions Groups (SG) presented the practical findings and recommendations you will find in this summary report, and facilitated dialogue to which over 120 cleft professionals contributed. We were pleased to host 2 of our 6 Roundtables *en español* for the first time.

The immense stress currently affecting families and cleft professionals alike was a theme woven through our discussions. In light of this, Prof. Nichola Rumsey's (OBE, PhD) [opening plenary](#) session on *Promoting Resilience in Patients and Families: A new focus for care* was most stimulating and apt.

S4CCC's wise International Advisors ably ended our time together in the [closing plenary](#) with insightful remarks about the importance of innovative global collaboration in the face of the pandemic, and their hopes that these conversations will lead to further progress.

We're pleased to report that S4CCC participants have assessed this conference positively, with [94% of participants](#) and Solutions Group members keen to make a priority of the next conference. Thankfully, you don't have to take our word for it – the S4CCC [YouTube Playlist](#) is up and running. We also offer this written summary of S4CCC highlights as a spur to further innovation and learning amidst the ongoing disruption of COVID-19.

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**PS.** The CoCP recognizes that vaccination progress, starting with health workers, is the way forward in every context. We are proud to raise our voices together in advocating for [global vaccine equity](#).

## Journey to S4CCC:

# COVID & Beyond



**\*SG:** Solutions Group of 6-8 diverse interdisciplinary cleft professionals exploring a key pandemic-related challenge facing LMIC contexts.

**\*\*QiqoChat:** Interactive Conference Platform

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# 2021 COVID Survey Highlights

The CoCP's goal is to better support the ability of CCC teams in LMIC contexts to care for all affected by cleft lip and palate.

In February of 2021, the CoCP sponsored a COVID survey in 6 languages, to gather information on how multidisciplinary cleft professionals were experiencing and managing the unprecedented disruption of the pandemic.

We received responses from **175 CCC professionals**, of which **74% were from 40 LMICs** and **26% from 10 HICs**.



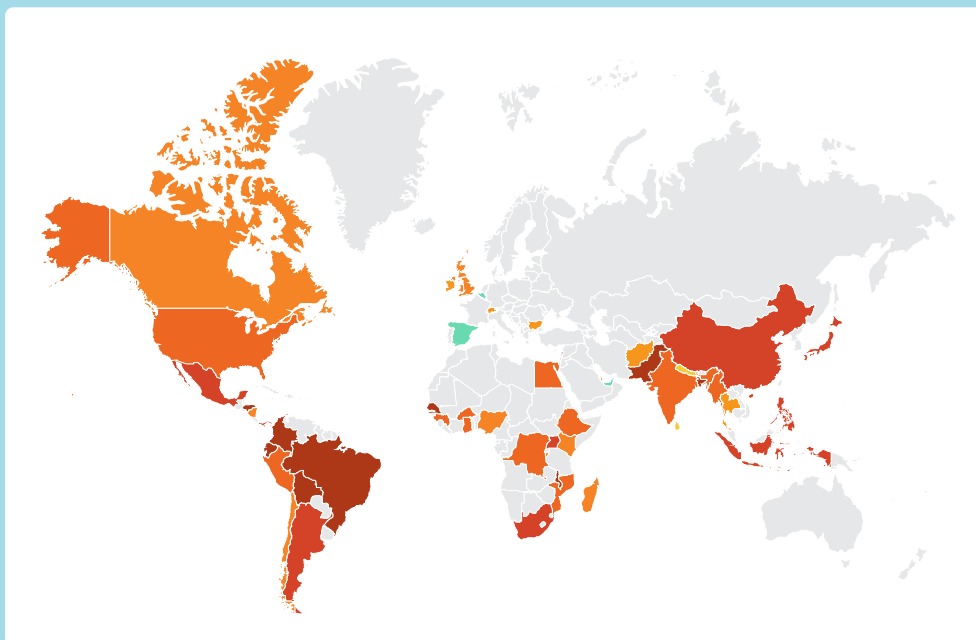
## Key Survey Findings

- **74%** of respondents have witnessed a decrease in the number of cleft patients being treated or supported
- **56%** point to a decrease in the quality of care cleft patients receive
- **7.5%** are unable to support any cleft patients due to the pandemic
- Half (**50%**) of CCC professionals have experienced a reduction in income for cleft work

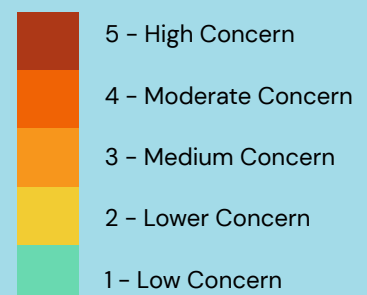
## How Concerned are Cleft Professionals?

CCC professionals are **Very Concerned** about implications of COVID-19 for cleft care within their local country context (Average rating: 4.02 on a 5-point scale), stemming from:

- **Heightened anxiety** amongst patient families due to treatment delays
- **Economic hardship** and increased transport costs
- Growing **patient backlog**
- Experience of **burnout** among cleft colleagues



Overall, cleft professionals from LMICs were **17%** more concerned than those from HICs about the local implications of the pandemic upon cleft care.



## SG1 Summary

# Augmenting Telehealth Strategies for Patients with Cleft



### IN THIS SECTION:

[Solutions Group Members](#)

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# OBJECTIVE

Our aim is to facilitate a discussion of practical solutions to telehealth that will assist cleft professionals in LMICs to extend Comprehensive Cleft Care (CCC) amidst the pandemic.

## CONTEXT

The CoCP's 2021 CCC Survey Results indicated that telehealth emerged as a top interest area for further learning (LMIC respondents: 63%, HIC Respondents: 59%).

Pre-pandemic literature about telehealth was mainly based on experiences in HICs. Due to COVID, there was rapid deployment of telemedicine globally, including in LMICs. This SG explored systematic reviews and scoping reviews pre and during the pandemic, in addition to accessing WHO and policy documents. There is an urgent need for global consensus on cross boundary protocols, cleft telehealth guidelines, monitoring, evaluation, data security, confidentiality and privacy, consent, professional accountability and liability.

The Solutions Group (SG) work was based on a range of different disciplines' experiences based on the last 8-12 months, from 4 continents, all at a different stage in the development of telehealth.

### 3 sub-areas of interest were identified as the focus:

1. Telehealth challenges/solutions
2. The ethics of telehealth
3. Defining telehealth and its uses

### The Roundtable poll (33 respondents) revealed that:

- 77% of participants are comfortable using telehealth
- 61% were using some telehealth prior to the pandemic
- 54% have not received any training on how to provide telehealth services
- 76% feel their region is ready for telehealth



# FINDINGS

## Example from Bangladesh

### SURGERY

- Pre-pandemic, telehealth provision was sporadic.
- With the onset of the pandemic, systematic management of nutrition, general health/surgical consultation, oral hygiene, feeding techniques, and psychological support to parents became key priorities.
- Poor mobile networks, lack of access to smartphones, and constraints of poverty are ongoing challenges to telehealth provision.

## Example from Thailand

### SOCIAL WORK

- Cleft care that requires crossing international borders (e.g. Myanmar/Thailand/Laos) is not possible during a pandemic.

## Example from Ethiopia

### NUTRITION

- Telehealth is a new practice for cleft patients in Ethiopia, telehealth through telephone is a recent example.
- Telehealth can be successfully employed for cleft patients struggling with malnourishment.

## Example from Mexico

### SURGERY

- Telehealth employed for assessment, evaluation and some interventions (e.g. psychology and speech therapy).
- Professionals can learn how to communicate effectively via virtual meetings.
- Dental and surgical work continued in person.

# RECOMMENDATIONS

## Example from Bangladesh

### SURGERY

- Use a mix of **Facebook**, mobile phone support and email to provide support to parents.
- **Parental support** can include feeding techniques, oral hygiene guidance, and overall psychological support.
- Collaborate **globally** and regionally to improve telehealth, but solve challenges **locally**.

## Example from Thailand

### SOCIAL WORK

- Employ a **mix of apps**: Facebook, LINE (similar to WhatsApp) and one-to-one video counselling.
- **Online “camps”** and activities can be substituted for in-person cleft care group gatherings for families.
- Consultation for hearing, dental and nutrition concerns can be provided online.
- **Group fundraising** and projects (e.g. facemask making or fund distribution for purchasing face shields for local hospitals in need) can be an engaging online activity.

## Example from Ethiopia

### NUTRITION

- Create a free **landline hotline** through which patients can be connected to nutrition advisors.
- Provide **counselling** on topics such as positioning of child for effective latch, breast milk expression and balanced diet along with strict weekly follow-ups by phone.

## Example from Mexico

### SURGERY

- Freely share patient and team **safety protocols** among cleft and craniofacial organizations to ensure global safety of patients and professionals.
- Provide adequate PPE for patients and professionals for critical **in-person procedures**, but use phone calls and video-conferencing for screening and follow-ups.
- Use WhatsApp, video cameras, tablets and microphones to provide **post-surgery SLP care**.

Continued ►



# FINDINGS

Example from Lebanon, Ecuador & Peru

## DENTISTRY

- Primary follow-up and consultations were completed via teletherapy for surgery, nutrition, speech, psychosocial, and dental care, using WhatsApp, FaceTime and Zoom.
- Telehealth tools can help guide local surgeons and enhance teaching and training opportunities.
- Electronic Medical Record (EMR) platforms allow professionals to access key information and to provide follow-up irrespective of their location.

Example from India

## SPEECH

- There is a huge “digital divide” among countries and regions regarding access to and understanding of technology.
- Time zones can make virtual care difficult to schedule cross-regionally.
- Telehealth policy and guidance varies from region to region.

# RECOMMENDATIONS

Example from Lebanon, Ecuador & Peru

## DENTISTRY

- Provide **pre-surgical taping guidance** to parents and follow-up via WhatsApp.
- Host **parent/patient support groups** via WhatsApp and Facebook.
- Use **video conferencing** to communicate warmth, demonstrate personal care, and enhance the psychological support to parents.
- Employ platforms like Instagram Live and Facebook Live for **educational video teaching**.
- **Augmented reality surgery** can allow a US-based surgeon to virtually “scrub-in” to assist and guide a surgeon on the ground, subject to all prerequisite requirements being in place.

Example from India

## SPEECH

- Start with a **needs assessment**: availability of technology + suitable environment for virtual therapy (lighting/noise/privacy).
- Make use of systems and tools that are **used by families** to support online education in their region.
- Develop **short videos** for preparing the families for tele-intervention.
- Use a **hybrid model** (telehealth and in-person) whenever possible.
- Make enrolment forms, consent forms, training materials available virtually.



# KEY QUESTIONS FROM PARTICIPANTS



## How can we provide care to clients despite internet issues?

- Scale down technology where internet connectivity is not possible (e.g. use phone calls). Focus on what is widely available in your region.
- Upload videos vs. relying on a live stream – uploaded videos do not require as much bandwidth.
- Be flexible in service delivery protocols based on local constraints (bandwidth, travel, etc).

## By which other means can we help families in rural areas when access to smartphones etc. is near impossible?

- Develop training manuals for clients (e.g. how to join a conference call).
- Provide tablets to community champions/ local volunteers.

## How do we monitor patients post-op?

- Train community members to care for patients with cleft.
- Provide live online training for nurses which can be recorded and used as a long-term resource.
- Post-op follow ups can be done via telehealth.

## What are some strengths and potential solutions for delivering Comprehensive Cleft Care using a telehealth approach?

### Strengths of telehealth model:

- Reaches more patients.
- Reduces travel costs.
- More touchpoints with families and opportunities for individualized care.

### Solutions/Opportunities:

- Families take an active role in their own child's care.
- Leverage community health workers to help equip families with devices for telehealth consultations.
- Be flexible – switch between synchronous and asynchronous strategically.
- Promote networking among families – they can empower one another.
- Mail educational materials to families.
- Collaborate with telephone companies, internet companies and NGOs to improve access to devices for low-income families.
- Centralize educational/training resources to expand reach.
- Provide telehealth training to professionals and parents and community health workers.

Watch SG1's Roundtable →

## SG2 Summary

# Assessing Patient Outcomes During the Pandemic

## SOLUTIONS GROUP MEMBERS



### IN THIS SECTION:

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## OBJECTIVE

Facilitate a discussion of practical solutions for assessing patient outcomes during the pandemic that will assist cleft professionals in LMICs to extend Comprehensive Cleft Care (CCC) amidst the pandemic.

## CONTEXT

Despite initial optimism that some LMIC contexts would be spared successive waves of the pandemic, it is clear that cleft professionals will be adapting their practice to COVID-19 constraints for some time. As a result, this Roundtable focused on how to ensure patients make progress in achieving their rehabilitative goals amidst this disruption and what evaluative tools and practices are most promising.

### Relevant CoCP 2021 Survey Results:

- **56%** of CCC professionals surveyed noted a decline in the quality of cleft care during COVID.
- **55%** noted that they face workplace restrictions that prevent regular service delivery.
- **75%** noted that families are facing fear and stress due to pandemic-related treatment delays.

### Case Example:

## BRAZIL

- Educational materials about feeding and nutrition sent to parents and local health professionals.
- Virtual CCC team consultations are held with families visiting their local public health facility to facilitate pre-surgical nutritional assessments and other checks-ups closer to home.
- WhatsApp and video used for follow up between visits to the cleft centre.
- Speech therapy and assessments conducted through video conferencing.



# FINDINGS

## ORTHODONTICS/ORAL HEALTH

- Minimum elements of orthodontic assessment include: clinical photographs, oral health assessment, radiographs and study models.
- Concern from patients/caregivers about postponed or prolonged treatment.
- Despite limitations, orthodontic follow up and assessment is possible virtually (phone, video, WhatsApp, photos).

## SPEECH THERAPY

- It is generally possible to follow regular outcome evaluation timelines during the pandemic.
- Minimum assessment components include: auditory-perceptual assessment of articulation and nasality based on standard test items, informal observation based on connected spontaneous speech, informal check-in on psychosocial well-being.

## SURGERY

- Key considerations: impact of COVID on timing of surgical treatment and approaches to maintaining routine evaluation.
- Engagement with families regarding their outcome evaluation expectations, and their 'from-home' contribution is important.

## NUTRITION

- Patient outcomes highly dependent on parents' level of knowledge about cleft nutrition.
- Weight gain is crucial for timely surgery and must be monitored during COVID.

# RECOMMENDATIONS

## ORTHODONTICS/ORAL HEALTH

- Provide instructions for the patient/caregiver for taking **extraoral and intraoral photos** (using retractors when possible).
- Use **before and after photos** to assess teeth alignment and treatment problems remotely.
- **Maintain ongoing communication** to address parental concerns about delays or prolonged treatment plans.
- Provide patient/caregiver with **oral hygiene instructions**; assess oral hygiene and dental issues through conversation with caregivers.

## SPEECH THERAPY

- Carefully consider best practices for **telehealth assessment procedures** (e.g. external noise control, microphone positioning).
- Switch off **audio filters/enhancements** when recording tele-speech assessment, if applicable on your device/platform.
- Use **sound recordings** to check/ corroborate your online auditory-perceptual assessment.
- **Follow** the data retention and management procedures of your institution.

## SURGERY

- Use **telemedicine recordings** as sources of outcome evaluation data.
- Share **data collection methods** and data itself (e.g. speech recordings to evaluate surgical outcome or photos for surgery and dental outcomes).
- Develop **minimum standards for clinical photographs** taken at home.
- Long-term: consider potential web interface that allows patients to upload their own data/photos.

## NUTRITION

- Educate parents on **danger signs** so they know when to report to a health centre; assess their knowledge during hospital visits.
- Birth weight and regular weight checks can be done at the family's **nearest health centre** in coordination with the cleft team.
- Weight gain should be charted against height/length **growth indicators**; Middle Upper Arm Circumference measured for older children (with MUAC tape provided to parents to take home where possible).

# KEY QUESTIONS FROM PARTICIPANTS



The requirements for oral health and orthodontic outcomes seem like they may be challenging during COVID (i.e. x-rays, intraoral photos). What are some innovative ways to still provide these assessments?

- Carefully consider the objectives of your evaluation in light of the age of the patient. Seek to consolidate evaluation timelines with other discipline treatments.
- Outcome evaluation should not add burden to families, so combining audit and check-up appointment data is a high priority.
- Consider surveying families to ask how telemedicine is (or isn't) working for them.
- Collect PROMS (patient-reported outcome measures), especially related to remote data collection. PROMS questionnaire data is actually the easiest outcome data to collect in contrast to measurements, images and audiovisual data.
- Standardize how we take oral photographs and prepare step-by-step instructions for parents to follow to get the best images and sound possible.
- A hybrid in-person/telehealth model could be beneficial and reassuring to families about COVID safety.
- Challenges identified:
  - ▶ **Equitable access to smartphone / webcam / bandwidth / data** cannot be assumed across LMIC contexts, especially in vulnerable communities.
  - ▶ No standardized guidelines for how to **take photos / videos at home**.
  - ▶ Some parents and caregivers might need **coaching and technical support** to provide evaluation data from home.

There are an impressive number of outcome measures described in this presentation, spanning multiple specialty areas. Will it be possible to compare outcomes before and after COVID (treating COVID as a 'natural experiment')? Or are there too many confounding factors involved?

- In many contexts, parents/caregivers are contributing towards a detailed evaluation. Some participants noted that they have more information from patients and more evaluation than prior to the pandemic.
- In some contexts, telehealth has ensured better access for patients who ordinarily would be required to travel long distances.
- Prioritizing the outcomes we should measure (vs. we can measure) is a key challenge.
- Pre- and post-COVID outcomes could be assessed with a similar recorded speech sample for similarly aged patients.

**How are teams ensuring patients are seen within key times during the pandemic?**

- Deliver telehealth support wherever possible, especially with speech. This is safer for all.

**Are there outcomes that are more important that we need to prioritize? How do we determine which should be prioritized?**

- For speech, prioritize assessing articulation, nasality, spontaneous speech and continue checking in with the patient.
- The SG sought to prepare **guidelines** in a way that they could be applied in both low-resource and well-resourced contexts, without losing key touchpoints (even amidst the pandemic) wherever possible. There is room to add more to the guidelines, where resources allow.

Continued ►



## Questions Continued:

### What are the challenges for outcome evaluation in contexts where internet access is unreliable?

- In the Ethiopian context, until everyone has better access to the internet, **landline or mobile phone** is the best alternative.
- Pandemic challenges and lack of internet (and sometimes even phone access) in Ethiopia has left the team with a lot of backlog for speech and orthodontics.
- In some rural areas, there are no landlines, no mobile/data, and sometimes no electricity, making it very difficult to reach patients virtually. More advocacy is needed to strengthen **global broadband access**.
- In Chile, the cleft team is utilizing **medical students** to keep in touch with the parents and teenage patients, and provide support between appointments by conducting phone calls to ask parents what they need (e.g. resources, time from specialists, resources, voicing concerns / fears) and documenting this data. The cleft team is currently designing a formalized **interview questionnaire** to ensure they collect consistent data.

### In many contexts, programs are trying to spearhead free, national or local cleft hotlines. Could this be expanded to collect outcome assessments?

- There is history in the UK of using telehealth hotlines for nutrition support in remote communities. A benefit is **trust-building**: when an in-person treatment occurs, the families feel they already know the professional.
- Telemedicine can increase the **confidence of local health visitors** / field workers in supporting children with a cleft. It is easier to demonstrate that they are collecting data and delivering care accurately.
- In well-resourced contexts (e.g. the UK), certain platforms such as WhatsApp are not permitted for telehealth. In Chile, WhatsApp has been found to work when regular phone calls aren't consistently available in rural contexts.

### How is COVID an opportunity for knowledge sharing?

- COVID has been a game-changer in the ability to share knowledge from around the world.

- Opportunity to share knowledge from the Global South about the importance of using tools like WhatsApp, so that countries in the Global North (e.g. UK) can make a case against bans of their use in telehealth.

### Is COVID an opportunity to get agreement on international outcomes in cleft and, if so, are we any closer to that goal?

- Agreement on the need to **democratize international outcomes studies** by standardizing a) what we collect and b) the outcomes studied from this data is needed. The pandemic could be an opportunity to make this happen.
- Call for basic recommendations for photographs that can be taken in low-resource, non-hospital settings, noting that the perfect lighting, standard background, etc. are not essential.
- A **mobile app** could be one way to collect standardized outcome data globally.

### What is the main barrier for standardization? Does it need to be top down or bottom up?

- Empower cleft teams to **publish research** and encourage more of these types of forums. More pre and post COVID outcome comparison data is needed.
- Gather guidelines that are representative of contexts around the world.
- Start small and acknowledge that we can't do everything at once.
- Prioritize: a) ages – WHEN is the best time that different disciplines most want to collect data; b) then HOW we collect it; c) then WHO is going to measure it?
- **Quality Improvement (QI) methodology** might be a way forward (e.g. plan, study, act, do could be helpful to evaluate your service) without the time and difficulty of relying on peer-reviewed journal articles.
- Measure speech activity and participation, not just speech impairment.
- Give parents **simple and clear instructions** for how to collect useful data and outcome measures. Some information (e.g. photos/videos) with less quality and standardization is better than nothing!
- Collect **raw data**. In-clinic, subjective assessments by the treating cleft team without raw data collection means that there is no possibility for independent unbiased, outcome assessment.



## NEXT STEPS / FURTHER INQUIRY

- Comprehensive Cleft Care (CCC) remains a priority despite the pandemic's limitations.
- Technology can be used to measure outcomes comprehensively and promote team coordination (e.g. virtual speech therapy can also be an opportunity to assess surgical and nutritional outcomes).
- Cleft professionals must publish findings to continue strengthening pandemic-inspired processes.
- More advocacy needed to promote global reliable broadband access to facilitate remote outcome evaluation.



## TOOLKIT

[Surgery Considerations →](#)

[Speech Guidelines →](#)

[Nutrition Guidelines →](#)

[Orthodontic Guidelines →](#)

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[Watch SG2's Roundtable →](#)



## SG3 Summary

# Adapting and Refining Cleft Care Protocols



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[Toolkit](#)

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Scribe: **Ms. Paige Holmes**

# OBJECTIVE

To provide solutions and recommendations for cleft care protocols during COVID-19 concerning patient and professional safety as well as surgery and Comprehensive Cleft Care (CCC).

# CONTEXT

The pandemic has created a backlog of children requiring services and there is a global need to prioritize urgent aspects of cleft care. There is currently little scientific literature focused upon cleft care provision during COVID-19.

Compared to March 2020, there is a much better understanding of COVID-19. Many countries have developed protocols for providing safe treatment during the pandemic. In terms of cleft management, a variety of factors will influence these protocols, including:

- Differences in local healthcare services.
- Socio-economic and cultural contexts.
- Availability of multidisciplinary care.
- Dependence on external teams for cleft care (i.e. when local services do not provide care).

**The principles and priorities for safety were determined using:**

- International references (e.g. CDC, WHO, NIH).
- Contemporary, peer-reviewed literature.

**The principles and priorities for surgery and CCC were determined using:**

- Available CCC guidance.
- Available functional outcomes-based evidence.

## Case Example:

## CHILE

- During the most critical period of the pandemic to date, all in-person cleft care was halted while some telehealth services were provided.
- As cases started to drop, primary cleft surgeries were prioritized and telemedicine support was maintained for some patients.
- In-person care protocols:
  - ▶ Nurses complete phone-based negative symptom questionnaire with patient before surgery.
  - ▶ Patient must have negative PCR test 24-48 hrs before surgery with no symptoms of COVID-19.
  - ▶ PPE, social distancing, mouth covering, and hand sanitizing at the hospital were enforced.
  - ▶ Restricted circulation for students, staff, and patients.
  - ▶ Surgical times shortened.
  - ▶ Study completed for teaching students using Go-Pro cameras.
- Out of 113 surgeries in 2020-2021, 2 PCR COVID-positive patients after cleft procedures.
  - ▶ No traceability from patient to professionals.
  - ▶ Exposure likely occurred after they had left the hospital.



# FINDINGS

## GLOBAL EXAMPLE

- Before COVID-19, Operation Smile (OS) treated as many patients as possible according to NGO priorities.
- By March 2020, all OS international and programs stopped; many local programs were also halted.
- Currently OS is in the “Yellow” phase, proceeding with caution.
- Pre-COVID-19, OS required Complete Blood Count (CBC) bleeding assessment.
- Now: OS added in RT-PCR testing (during and after COVID-19).
- OS results:
  - ▶ No morbidity/mortality associated with COVID-19.
  - ▶ One program was cancelled due to positive exposure.
  - ▶ Any customary complications from surgery/anesthesia were not attributed to viral spread.
  - ▶ OS has now opened up some local programs, exploring opening international programs on a needs-basis.

## COMPREHENSIVE CLEFT CARE

- Most current evidence regarding pandemic CCC protocols is low-grade evidence.
- The priority is to adapt protocols to minimize hospital visits/stays and to maximize everyone’s safety.
- Some contexts are able to offer care remotely via telehealth.

# RECOMMENDATIONS

## GLOBAL EXAMPLE

- Continue CBC bleeding studies, and RT-PCR testing for patients as pandemic continues.
- Continue RT-PCR testing for staff and volunteers as pandemic continues.
  - ▶ May not be needed if staff and volunteers are fully vaccinated.
- Consider the following prior to restarting cleft surgical programs during/after COVID-19:
  - ▶ Availability of appropriate PPE (ie. N95 masks).
  - ▶ Adequate hygiene.
  - ▶ Access to COVID-19 testing.
  - ▶ Vaccination status of community and healthcare workers.
  - ▶ Ability to care for patients/staff who test positive for COVID-19.
  - ▶ If staff/patients have the ability to isolate/quarantine should they test positive for COVID-19
  - ▶ Travel to certain countries may be limited depending on one’s home country status (e.g. professionals from certain countries may be prohibited from entering or returning from other countries)

## COMPREHENSIVE CLEFT CARE

- Adopt protocol for assessing priority (high/medium/low) of surgical procedures.
- Adopt protocols for priority of access (high/medium/low) to services (especially in-person services).
- Consider use of remote access or telehealth services for some components of cleft care (e.g. routine assessments, consultations, or screenings, some components of speech therapy).

# KEY QUESTIONS FROM PARTICIPANTS



**Will opening local programs, while international programs remain inactive, encourage a positive response/inspire the creation of more local programs?**

- Part of Operation Smile's (OS) program is to **train local surgeons** to deliver care. The pandemic may indeed encourage more local programs to open up across the world. Participation in OS missions will continue on an as-needed basis (according to safety protocols and qualifications of professionals).

**How has protocol changed if a patient developed COVID-19 during cleft-related treatment?**

- When patients developed **COVID-19 post-release** from hospital, they conducted **contact tracing** for other patients/staff in close contact with positive cases and determined that exposure occurred post-release; positive tests prior to surgery resulted in the delay of surgery.
- When two patients **tested positive during care**, both recovered well and there were no lasting psychosocial or financial impacts to their family due to COVID-19 exposure.

**What is the current protocol for safety and Comprehensive Cleft Care in the African context?**

- In Ethiopia, screening occurs before surgery; patients are not admitted without a negative test. **Priority** amidst backlog is given to **cleft palate surgery**. Telephone calls used for follow-up: parent coaching (e.g. in regards to orthodontics, oral hygiene, etc) and speech therapy.
- In Nigeria, the pandemic halted surgeries and other cleft care for a few months. Later, cleft care was delivered with caution; fewer patients, PPE and testing of patients emphasized.

**What are the implications of return to care regarding speech therapy in Chile?**

- **Building rapport** with new families over teletherapy is challenging. Oral assessments are more difficult via telemedicine. Priority for in-person nasendoscopy.

**Can you describe procedures/priorities for pediatric dentistry in Brazil?**

- Complete COVID screening before offering services. A slight increase in need for dental care/cavities has been noted. **Social distancing rules** have halved the number of dental chairs being used, with shorter appointments overall to allow time between patients. Surgeries have now increased to 106 vs. 80 per week.

**How have surgery numbers changed in Chile during the pandemic?**

- Surgeries for non-cleft abnormalities have dropped dramatically. The age for palate surgery has been raised slightly (1 year), which will have a large impact on speech and language outcomes.

**What protocols are most difficult to maintain when the COVID situation appears to be somewhat indefinite?**

- Testing protocols may not persist in a few years, due to herd immunity. High-resource countries should support areas with fewer resources regarding vaccination, and vaccines for young children will hopefully become available in the next few years. Acute dental infections/problems are dealt with immediately whereas less acute problems are dealt with less urgently.

**Should the definition of urgency be considered different now, as compared to the beginning of the pandemic (e.g. CLP surgeries should be considered more urgent)?**

- Categorization of CLP surgeries in the UK has shifted in the last few months to acknowledge **urgency of surgeries**; need for advocacy to policy makers in regards to urgency of surgery. **Vaccine inequity** remains a large problem in LMIC.



## TOOLKIT

### Can We Prioritize the Cleft Care Protocol?

Though we cannot be prescriptive about a cleft protocol, we can reach a consensus to prioritize certain aspects of the protocols suggested below, such as:

- Essential function
- Appearance
- Advocate adaptations for remote access in the setting of rigorous patient selection



### NEXT STEPS / FURTHER INQUIRY

- Determine how vaccination efforts will affect safety protocols.
- Continue to adapt and modify protocols based on the current status of COVID-19 severity in each country.

Download This Toolkit ↓

## TIMELINESS OF SURGICAL PROCEDURES

### Priority of Timeliness

### Procedures

### Outcomes-Based Evidence

HIGH

- Respiratory access if required in PRS
- Mandible distraction if required for nutrition
- Primary cleft palate repair (+ - middle ear tubes)

- Life-saving
- Feeding
- Speech and growth

MEDIUM

- Primary lip repair
- Secondary speech surgery
- Symptomatic fistula repair
- Secondary alveolar bone grafting

- Psychological bonding and oral continence
- Speech
- Speech and feeding
- Canine support

LOWER

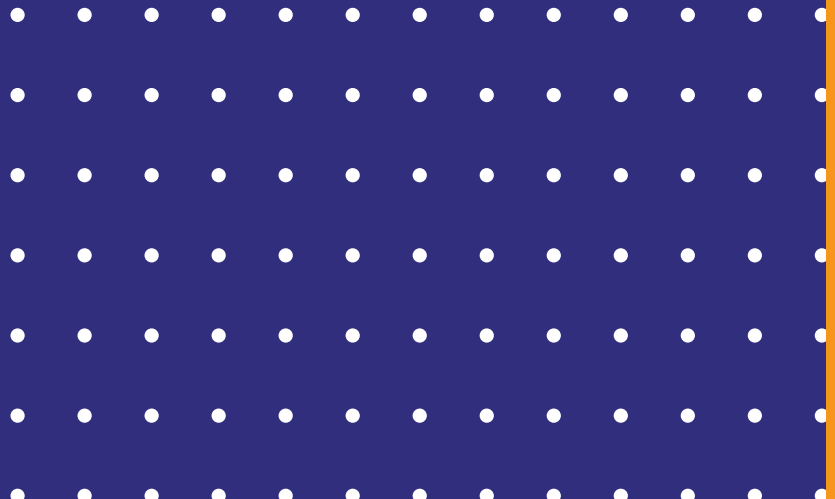
- Orthognathic surgery
- Secondary rhinoplasty and revisional surgery

- Mainly cosmetic outcome and functional outcomes not linked to timeliness of surgery

# ACCESS TO COMPREHENSIVE CLEFT CARE

Priority of Access	Elements of the CCC Protocol	Potential for remote access or tele-health?
<b>HIGH</b>	<ul style="list-style-type: none"> <li>Newborn cleft assessment for breathing, feeding, hearing and counselling</li> <li>Ongoing paediatric and nutritional support care (especially for syndromes)</li> <li>Dental or ENT infections (otitis media)</li> <li>Speech Pathology assessment and intervention</li> </ul>	No No No Maybe
<b>MEDIUM</b>	<ul style="list-style-type: none"> <li>Pre-surgical orthopaedics (if used within local protocol)</li> </ul>	Maybe
<b>LOWER</b>	<ul style="list-style-type: none"> <li>Routine audiology, dental and orthodontic assessment and advice</li> <li>Routine psychosocial screening</li> <li>Genetic counselling</li> </ul>	Yes Yes Yes

Watch SG3's Roundtable →



## SG4 Summary

# Promoting Parental Engagement During the Pandemic



### IN THIS SECTION:

[Solutions Group Members](#)

[Objective](#)

[Context](#)

[Case Example: India](#)

[Findings](#)

[Recommendations](#)

[Key Questions](#)

[Additional Solutions](#)

[Next Steps / Further Inquiry](#)

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**Host: Ms. Megan Janecka**

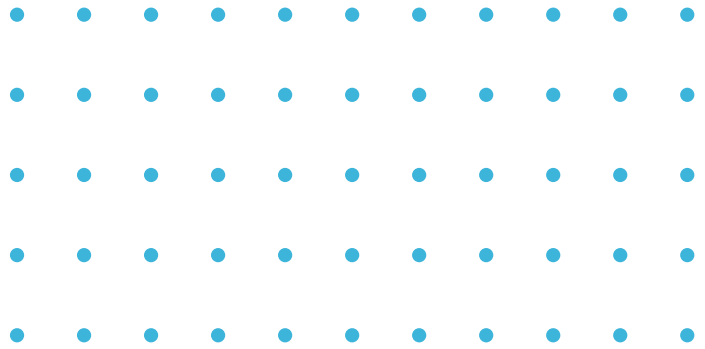
Special Projects Coordinator, Transforming Faces, Masters of Public Health Student, University of Waterloo

📍 CANADA

Scribe: **Ms. Hiba Najeeb**

# OBJECTIVE

Facilitate a discussion of practical solutions to promote parental engagement that may assist cleft professionals in Low-Middle-Income Countries (LMICs) with extending Comprehensive Cleft Care (CCC) amidst the pandemic.



# CONTEXT

Keeping connected with cleft patients and parents is a critical challenge of the pandemic. Without in-person contact and demonstrations by professionals, parental acceptance and comprehension of CCC can be limited.

Two major resources for information were used:

- A theme template for obtaining information from 6 countries and 10 professionals/groups on their practices and experiences.
- Collection of open source resources from across the world that were targeted towards parents (including information from centres/charities/webpages).

## Case Example:

## INDIA

**Child required nasal hook prior to surgery but no aerosol procedures were being done due to COVID.**

- Parents had to take the responsibility of hooking & taping.
- Motivated them through pre- and post-surgery photos.
- Monitored through WhatsApp calls.
- Required a lot of motivation, encouragement and engagement on the part of the parents.

Surgery able to be successfully completed after nasal hook therapy.





# FINDINGS

- Parental access to information about COVID helps reduce misinformation and lessens fear surrounding COVID for parents.
- COVID information can be transmitted online, through in-person awareness campaigns, via peer counselling about COVID, in children-friendly leaflets about what to expect at the hospital (e.g. people wearing PPE).
- Parents' fear to travel, increased travel expenses, and lack of contact with hospitals/cleft centres was noted in several contexts.
- Safe travel information can be communicated prior to in-person appointments (e.g. hand sanitizing/ washing, social distancing).
- Centres that provide transportation support help ease parental concerns and facilitate access to CCC support.
- By preparing patients to wear PPE in advance, their anxiety about in-person care can be reduced.
- Parents can be equipped to take a more active role in their child's CCC treatment via telehealth.



# RECOMMENDATIONS

- Provide comprehensive, technology-oriented interventions that encourage parents/caretakers to take an active role within the treatment:
  - ▶ Provide material/information about the professionals involved.
  - ▶ Encourage their participation in the child's therapy.
  - ▶ Provide information about how to protect themselves during in-person appointments.
  - ▶ Adapt resources into animated resources to reach different contexts.
  - ▶ Translate resources into local languages to further the reach of information.
  - ▶ Communicate the importance of comprehensive treatment and how it will benefit their child overall.
  - ▶ Use telehealth in many different ways and encourage parents to give suggestions.
- Provide materials/information specific to the profession at each level of care to maintain engagement:
  - ▶ **For feeding/nutrition:**
    - Provide parents with a guide for nutrition, weight gain, feeding hygiene, and weighing and measuring children at home.
    - Provide access to cleft-specific bottles.
    - Make referrals to local feeding specialists (if available).
  - ▶ **For surgery:**
    - Highlight pre- and post-photographs to communicate the positive impact of surgery.
    - Communicate in advance that only one attendant can stay with the child post-operatively (re: COVID protocols).
  - ▶ **For hearing:**
    - Engage local networks of ENTs to ease the burden of travel.
    - Advise families to attend ENT consultations (where available).

Continued ▶

## Recommendations Continued:

- ▶ **For speech:**
  - Provide information on how to perform tasks at home.
  - Host workshops attended by local celebrities & SLPs to discuss the importance of speech and psychological well-being.
  - Provide teletherapy.
  - Request patients/families to record videos and send them to the cleft centre.
  - Train field workers to use video call platforms to support speech.
  - Provide booklets (e.g. 9 Reasons to Smile).
- ▶ **For psychosocial well-being:**
  - Provide instructions on how to perform tasks at home.
  - Encourage exploration of emotions and relationships between family members.
  - Host webinars to improve parental awareness.
- ▶ **For dental care:**
  - Provide video materials and educational programs on oral hygiene.
  - Activate a network of dentist/dental clinical officers to help assess and teach dental care.
- Employ varied modes of communication:
  - ▶ Conduct awareness campaigns about the importance of CCC.
  - ▶ Make leaflets and booklets available for families – about what type of intervention would be needed and timing.
  - ▶ Use Video, phone calls, telehealth, WhatsApp (audio + video).
  - ▶ Computer-based and online information (helps both parents and medical team acquire information for records).
  - ▶ Post posters in the community and online.
  - ▶ Conduct outreach through community radio shows, online and through in-person events.
  - ▶ Share phones/tablets to increase access to care.
  - ▶ Use speech therapy apps.
- **Overall:**
  - ▶ Provide telehealth counselling for comprehensive services wherever possible.
  - ▶ Provide transportation assistance to access in-person appointments.

## KEY QUESTIONS FROM PARTICIPANTS



**How was the video quality during group WhatsApp calls addressed – there tends to be a compromise in quality when more people are added which, in turn, could impact the quality of therapy provided?**

- Group sessions were not done for therapies that required keen observation, such as articulation therapy. Those were done one-on-one. Group sessions were mainly done to **motivate patients and their families**.

**How many times was engagement initiated from parents, if ever?**

- In **India**, there was initial hesitation but after 2–3 months of lockdown, there was a huge wave of participation and parents taking initiative. After 6 months of lockdown, there was a dip in engagement. In **Colombia**, it was initially hard to get parents engaged and to follow a set timeline of appointments. After giving parents resources, they were more empowered to initiate contact.

**Continued ▶**

## Questions Continued:

**At any time, was the pandemic more of a priority than CCC? If so, how did you manage this?**

- Initially, families thought clinics were closed and did not want to come in. With **telehealth guidelines** being communicated to them, they were better able to participate even while being in lockdown or quarantine.

**Did parents require teaching on how to use WhatsApp?**

- Most parents did not require much training/coaching on **WhatsApp** – it was relatively easy to use after an initial orientation.

**Will follow-up appointments post-COVID be affected, since receiving services at home might better suit families' comfort levels?**

- Most panelists agree that post-pandemic, there will be a **hybrid approach to care**. Necessary appointments will be done in-person and those appointments that are less so can be done virtually.

**How was lack of access to technology/apps in rural areas dealt with?**

- Regions are diverse and face different challenges. However, access to technology does change rapidly. Operate at the level of technology you currently have and be prepared to scale-up when the opportunity arises.

**How do we figure out what the parents want and what works best for them in terms of communication?**

- In Nigeria, pre-surgery, the parents' level of education and their language skills is assessed. The team then knows the most effective way and language in which to communicate with the parents throughout the child's care process.

**What should we not push the parents too far on in terms of engagement?**

- Parental fatigue** is a natural part of the process. When parents continue to be engaged and motivated, it can be assumed that the approach is working for them.

**What platforms were successfully used for virtual speech therapy? Was WhatsApp one of them?**

- WhatsApp was used only if the patient/family was unable to connect through any other platform. Video recordings of the task were sent beforehand, and the video call itself was used to clarify the treatment and ensure the parents understood what was being asked of them. Using WhatsApp can be advantageous for those who cannot read, as the "voice messages" function facilitates conversation.

**What are suggestions for those who do not use smartphones?**

- In the case of Malawi, parents/guardians report to **local volunteers** who connect with the cleft care team. Monthly visits are also done by the team for nutritional support, speech, and dental services. There is also a free hotline which parents/guardians could use to ask for support or to report issues.

**Can telehealth replace the interaction between the therapist and child? A lot of progress is due to the bond between children and their therapist.**

- Telehealth** is lessening the importance of face-to-face interaction during the pandemic and in the future it will **augment in-person therapy** rather than replace it.

# ADDITIONAL SOLUTIONS PROPOSED BY PARTICIPANTS

## Context in Nigeria

- Speak in the language that parents are most comfortable in:
  - ▶ Ensure resources, text messages, etc. are in the family's primary language.
  - ▶ Recognize that individuals might be proficient readers/writers in languages other than English.
- Provide livelihood training (e.g. sell beads or how to keep up a farm) to support their family and child when jobs are lost.
- Offer emotional support to mothers so they can better support their child.
- Send regular check-in text messages as sometimes parents reply with questions or comments.
- Use social media platforms to reach out.
- Train and host parental support groups to encourage and empower parents and free up clinician time.

## Context in Brazil

- Use local healthcare professionals and resources to connect with patients and families, as well as interact with patients in-person before launching telehealth services.
- Request that families seek out local professionals to help teach techniques/strategies recommended by the CCC team, as teaching via video is difficult at times.
- Assign one person to contact each family for cell-phone training.
- Encourage use of 2 cell-phones when possible – one for talking with the team, and the other for sending images.
- Pursue partnerships with schools, libraries, churches, NGOs to increase family access to technology, especially for speech therapy.
- Assess speech patients before starting telehealth therapy; this makes it easier to engage virtually.

## Context in Malawi

- Use all available human resources to maintain connections with parents and families.
  - ▶ Equip volunteers (referred to as “champions”) to provide encouragement to parents and guardians.
  - ▶ Train multipurpose workers to provide information on nutrition, support, and connecting with the hospital.



## NEXT STEPS / FURTHER INQUIRY

While services have adapted to provide information to parents in various ways, some questions remain:

- How well did these adaptations work?
- How do we know they supported parental engagement?
- How can these resources be adapted for your service?
- What else should be explored or developed on this topic?

Watch SG4's Roundtable →

## SG5 Summary

# Augmenting Telehealth Strategies for Patients with Cleft

Facilitated  
and Presented  
in Spanish



### IN THIS SECTION:

[Solutions Group Members](#)

[Objective](#)

[Context](#)

[Case Example: Chile](#)

[Findings](#)

[Recommendations](#)

[Key Questions](#)

[Next Steps / Further Inquiry](#)

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Co-Chair

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### Host: Mr. Abdon Aguillon

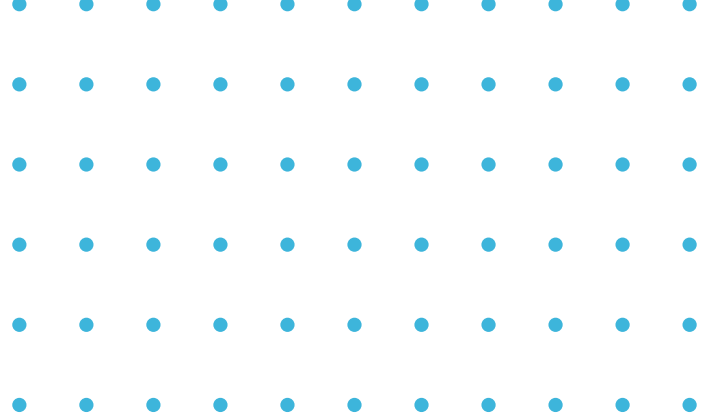
Program Director, Transforming Faces

📍 CANADA

Scribe: Dr. Lillie Elizabeth Abanto Silva

## OBJECTIVE

To facilitate a discussion of practical solutions to strengthen telemedicine in the different specialties in multidisciplinary management that will help cleft professionals in LMICs to extend Comprehensive Cleft Care (CCC) during the pandemic.



## CONTEXT

The CoCP's 2021 CCC Survey Results indicated that telehealth emerged as a top interest area for further learning (LMIC respondents: 63%, HIC Respondents: 59%).

This SG also initiated a Speech and Language Therapists Intervention during the COVID-19 Pandemic survey. **152 professionals** from **20 countries**, mostly from Latin America, contributed to this tool.

### Case Example:

## CHILE

#### Innovative Telehealth platform “Practica en Linea” was created:

- With support from municipal grants, SIM cards were delivered to patients enabling them to access the internet.
- The platform provides virtual rehabilitation to cleft patients, allowing health professionals and patients to have their own accounts. Additionally:
  - ▶ The professional attaches educational and informative content for the patient to use.
  - ▶ The patient can review the material that the professional has shared.
- A mix of online and offline audiovisual and visual digital material provided to support remote care of patients with cleft.



## FINDINGS

- Access to telemedicine is still limited in some countries. Internet access is not consistent across regions.
- The implementation of therapy support groups delivers strong results for patients.
- Incorporating recreational activities leads patients to demonstrate greater investment and commitment towards the therapy. Educational videos from various health areas help patients accept treatment and leads them to demonstrate healthier habits.
- A hybrid model (face to face + telemedicine) is promising as a sustainable practise.
- The pandemic and requirements of telemedicine have been particularly exhausting for Speech Therapists.
- The use of applications popular with families (e.g. Zoom) may be restricted at health centers level due to the risks of cyberattacks.

## RECOMMENDATIONS

- **Network** nationally, with multicenter collaboration and feedback for telehealth. Invest in the **academic strengthening** of CCC professionals within a multidisciplinary team.
- Involve **social workers** and **psychologists** in patient care. Their understanding of the patient's situation will facilitate the intervention of the rest of the CCC team.
- **Equip and instruct caregivers/parents.** Involving them early-on sets a positive example and contributes to patient progress in the therapy. Technological tools used in therapy must be **caregiver-friendly**. Include **fathers** as well as mothers.
- Use **digital tools**: games, apps, youtube videos of other health areas (e.g orthodontics) and information brochures to engage patients and families in cleft care activity. Patient **progress can be monitored** using Apps. This reduces the **workload** of therapists in preparation.
- Distribute **digital content** to patients and caregivers **in advance of sessions** to increase their preparation for therapy (e.g. placement of cell phone in room) and facilitate better collaboration during the session.
- Protect **patient health data** within a 'code of ethics' for telehealth care that protects patients and professionals.





# KEY QUESTIONS FROM PARTICIPANTS



## What are promising practises as it relates to use of telehealth technology?

- Use online surveys to get patient and family input and feedback.
- Create a YouTube channel that patients can also access through a QR code.
- An interactive Electronic Medical Record (EMR), such as is in use in Bulgaria, helps to manage a national network of cleft specialists and contains 1400 patient and professional users.
- An EMR system helps the CCC team articulate and manage an individual patient therapeutic plan.
- Improving resources and technological access for Indigenous areas/areas with little internet coverage is a high priority.
- Cleft professionals should also consider copyright, as it relates to the creation of digital content.

- Patients are more committed to therapy activities when there is a playful element -- it increases their stimulation.
- Oral hygiene videos designed for children under 9 years old to help them form healthy habits.
- Hybrid models allow for prioritization of the most important support to be delivered virtually. Human contact should not be lost.

## What is the importance of psychosocial support?

- Teaching children and parents about how to improve their language skills and regulate their emotions has generated strong interaction and speech therapy progress.
- When children are self-aware about their feelings, they fall asleep more easily and demonstrate more resilience overall, including the challenges of cleft.

## NEXT STEPS / FURTHER INQUIRY



- Further investigation of the impact of teaching language and emotional self-regulation to cleft patients.
- Establishing how best to pursue a mixed modality/hybrid model of care in each discipline.
- The development of digital friendly tools that are accessible and focused on patients/caregivers of various ages.
- Research into the evaluation of the impact of various digital tools.

Watch SG5's Roundtable in Spanish →



## SG6 Summary

# Assessing Patient Outcomes During the Pandemic

Facilitated  
and Presented  
in Spanish



### IN THIS SECTION:

[Solutions Group Members](#)

[Objective](#)

[Context](#)

[Findings](#)

[Recommendations](#)

[Next Steps / Further Inquiry](#)

## SOLUTIONS GROUP MEMBERS



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Co-Chair

### Mrs. Carolina Rivera

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### Host: Dr. David Corral

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📍 ECUADOR

Scribe: Dr. Twigg Rosalia Lazarte Hesse

## OBJECTIVE

Facilitate a discussion of practical solutions for Assessing Patient Outcomes During the Pandemic that will assist cleft professionals in LMICs to extend Comprehensive Cleft Care (CCC) amidst the pandemic.

## CONTEXT

### Relevant CoCP 2021 Survey Results:

- **56%** of CCC professionals surveyed noted a decline in the quality of cleft care during COVID
- **55%** noted that they face workplace restrictions that prevent regular service delivery
- **75%** noted that families are facing fear and stress due to pandemic-related treatment delays

## FINDINGS

- Patients can be especially fearful because of the PPE worn by professionals during the medical consultation.
- Beyond patients and parents, telemedicine approaches can incorporate grandparents, other caregivers, and teachers.
- Telemedicine practices are likely to be sustained beyond the pandemic.

## RECOMMENDATIONS

- Strive to project a **friendly image** to patients and families for in-person appointments, despite wearing PPE. This will reduce patient fear during the medical consultation, without neglecting biosafety protocols.
- Invite **appropriate participation** of all caregivers and teachers into a telehealth approach. Create indicators to measure the participation of a patient's supporters.
- Use technological tools such as the Slack app or create interdisciplinary work links to promote **collaboration**.
- **Train caregivers** to contribute to patient outcome assessment.
- Find **alternatives for in-person assessments** (e.g. private clinic, following strict protocols) when hospitals are closed because of COVID.
- Initiate telemedicine to **reduce fear** of attending in-person consultations.
- **Involve administrative staff** as members of the CCC team. Their informed contributions can promote parental engagement and decrease stress of cleft professionals.
- **Provide** psychology consultations to patients, acknowledging that the pandemic is leading to increased anxiety and levels of depression.

## NEXT STEPS / FURTHER INQUIRY

- Carry out cohort studies of treatment progress in speech therapy (telemedicine vs. face-to-face), odontology, orthodontics, orthopedics and psychology.
- Initiate quality of life studies in post-pandemic cleft patients (post-surgical, dentistry and orthodontics).
- The pandemic is an opportunity to develop more preventative tools and to provide better instruction to parents about treatment plans.

Watch SG6's Roundtable in Spanish →

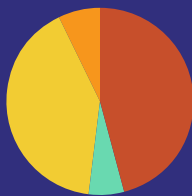
# Feedback Survey Summary

## PARTICIPANT FEEDBACK



### SURVEY RESPONDENT PROFILE (%)

Total number of Respondents: 68



- LMIC Participants: 46%
- HIC Participants: 6%
- SG Members (LMIC + HIC): 41%
- NGO Representatives (LMIC + HIC): 7%

	N/A	Unhelpful	Somewhat Unhelpful	Helpful	Very Helpful
QiqoChat/ Zoom Conference Platform	0%	0%	4%	30%	66%
S4CCC Plenary Sessions (Opening & Closing)	5%	0%	4%	36%	55%
S4CCC Roundtables	4%	0%	2%	29%	65%
<b>OVERALL S4CCC EXPERIENCE</b>	<b>0%</b>	<b>0%</b>	<b>3%</b>	<b>26%</b>	<b>71%</b>

### What Participants Appreciated:

*"The convenience of being able to share experiences with colleagues from all over the world from my own clinical setting."*

*"The getting together of so many disciplines from so many different countries. It is true to the word Comprehensive."*

*"Excellent organization and promotion of an inclusive friendly atmosphere."*

### Participant Next Steps:

*"Review alternatives to better implement telemedicine in my Centre."*

*"Speed up production of short educational videos."*

*"I would like to write a paper about my SG findings."*

### Participant Suggestions on Areas for Improvement:

*"Expand to more attendees in the next conference."*

*"Less overlap between SG Roundtables."*

*"Clearer articulation of homework and to-do list."*

94%

of participants  
are highly likely  
to attend a future  
S4CCC Conference

# SOLUTIONS GROUP FEEDBACK



## Achievement of SG Objectives:

Total number of Respondents: 28

	Not at All	Somewhat	Successfully	Very Successfully
Providing a time-bound, transparent workflow for S4CCC preparation	0%	4%	42%	54%
Facilitating global, interdisciplinary and cross-NGO cleft professional dialogue and learning	0%	4%	27%	69%
Focusing upon documenting practical tools with a LMIC focus	0%	15%	35%	50%
Stimulating innovation	0%	8%	27%	65%

### What SG Members Appreciated:

*"I really like the clear, time bound plan – that led to more being achieved than in Task Forces that don't have the same tight clearly defined timescales."*

*"Facilitating dialogue and global, interdisciplinary professional learning by putting aside the NGO you represent."*

*"Teams made up of different disciplines and from different countries and cultures, all dedicated to cleft."*

94%

SG Members are highly likely to participate in a future SG

92%

SG Members rated their overall experience of participating in a SG as excellent

### SG Members' Suggestions for Improvement:

*"Better ways of including the viewpoint of patients and parents."*

*"It would have helped if we had more time to prepare for the SGs."*

*"Sometimes it was hard to engage everyone and it was very difficult to plan how to move forward."*

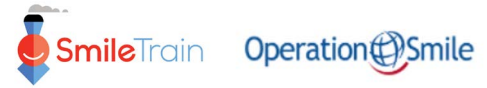
### S4CCC Team's Response to the Feedback

The S4CCC Team is grateful to all participants, SG Co-Chairs and SG Members for engaging with a new structure and working ethos for these Roundtables. There is room for improvement, yet insights from across continents and NGO affiliations indeed led to practical recommendations. Insufficient bandwidth, the challenges of navigating QiqoChat with a mobile device, and high workload demands during the pandemic limited the participation of some cleft professionals. We recognize that for SG members, adding time-sensitive and collaborative conference preparation work to busy agendas (amidst a pandemic) could be difficult to navigate.

# Acknowledgements

S4CCC is Presented by the Circle of Cleft Professionals (CoCP).

The CoCP is a worldwide network of cleft professionals and cleft charity leaders with an interest in promoting Comprehensive Cleft Care (CCC) in resource-constrained contexts.



## S4CCC ADVISORS

With a huge debt to the S4CCC International Advisors for their insights and encouragement, the vision for innovative online conferences was first established in June 2020: LMIC-rooted, interactive, learning-oriented, solution-focused.



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📍 CHILE



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Associate Prof. of Surgery SoM AAU, Plastic & Reconstructive Surgeon, Cleft Program Leader, Yekatit 12 Hospital Medical College  
📍 ETHIOPIA



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Head, Department of Plastic & Reconstructive Surgery, CoRSU Rehabilitation Hospital  
📍 UGANDA



**Dr. Felicity Mehendale**

Plastic, Reconstructive & Cleft Surgeon, U. of Edinburgh. Chair of Cleft 2022 and President of the International Confederation of CL&P and Related Anomalies (ICCCPA)  
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**Prof. Roopa Nagarajan**

Academic Officer and Professor, Department of Speech Language and Hearing Sciences, Sri Ramachandra Institute of Higher Education and Research, (DU), Chennai  
📍 INDIA



**Dr. Debbie Sell**

Senior Research Fellow/Speech Therapist, ORCHID, Great Ormond Street Hospital for Children, London UK, Co-Founder/Director of Speech@Home  
📍 UNITED KINGDOM



Plenary Speaker

Opening Plenary presented by  
**Prof. Nichola Rumsey**, OBE, PhD,  
University of the West of England  
📍 UNITED KINGDOM

Watch the Opening Plenary →

Watch the Closing Plenary →

# S4CCC Participants

## A

Ms. Gertrude Abbey, Ghana, Speech  
Dr. Mohamed Abd El-Ghafour, Egypt,  
Orthodontics  
Prof. Mamdouh Aboulhassan, Egypt, Surgery  
Mr. Abdon Aguillon, Canada, Cleft Charity  
Leadership  
Ms. Ayesha Aheaney Amartey, Ghana, Speech  
Dr. Youri Anastassov, Bulgaria, Surgery  
Dr. Melissa Antoneli, Brazil, Speech  
Ms. Roxana Aranguiz, Chile, Nursing  
Mrs. Tammy Aravena, Chile, Speech  
Ms. Rahma Arebi, Ethiopia, Speech  
Dr. Ruben Ayala, USA, Cleft Charity Leadership  
Mr. Chigozie Azunna, Nigeria, Cleft Charity  
Leadership

## B

Dr. Subramaniyan B., India, Speech  
Dr. Jayanth B.S., India, Surgery  
Dr. Suely Barros, Brazil, Nutrition  
Dr. Shiferaw Berbirssa, Ethiopia, Orthodontics  
Ms. Samrawit Berihun, Ethiopia, Speech  
Dr. Daniel Bradley, UK, Research  
Dr. Tim Bressmann, Canada, Speech  
Mr. Hugh Brewster, Canada, Cleft Charity  
Leadership  
Ms. Bernice Brown, Ghana, Speech

## C

Dr. Marina Campodonico, Chile, Orthodontics  
Dr. Krishnendu Chatterjee, India, Orthodontics  
Dr. David Corral, Ecuador, Dental  
Dr. Carolina Cramaro, Argentina, Surgery  
Dr. Gisele da Silva Dalben, Brazil, Dental

## D

Ms. Neeti Daftari, Canada, Cleft Charity  
Leadership  
Mr. Gareth Davies, France, Cleft Charity  
Leadership  
Dr. Maria del Carmen Pamplona, Mexico,  
Speech  
Dr. Jeniffer Dutka, Brazil, Speech

## E

Dr. Nancy Edith Rojas Holguín, Colombia,  
Orthodontics  
Dr. Lillie Elizabeth Abanto Silva, Peru, Dental  
Ms. Adelaide Emma Gyamera, Ghana, Speech  
Dr. Mekonen Eshete Abebe, Ethiopia, Surgery

## F

Mrs. Anis Fathima K., India, Manager/  
Coordinator  
Mr. Matt Fell, UK, Surgery  
Ms. Simone Fischbach, Canada, Speech  
Ms. Ludivina Flores Bonilla, Mexico, Speech

## G

Dr. George Galiwango, Uganda, Surgery  
Dr. Praveen Ganesh Natarajan, India, Surgery  
Dr. Zipporah Gathuya, Kenya, Anesthesiology  
Mr. Natnael Getnet, Ethiopia, Speech  
Mrs. Lakshmi Godavarthi, India, Speech  
Ms. Carmen Gloria Morovic, Chile, Surgery  
Mrs. Karen Goldschmied, Chile, Speech

Dr. Michael Goldwasser, USA, Surgery  
Mr. Matias Gonzalez, Chile, Speech  
Dr. Aracely Granados, Mexico, Orthodontics

## H

Dr. Usama Hamdan, USA, Cleft Charity  
Leadership  
Mrs. Midori Hanayama, Brazil, Speech  
Dr. Savitha Hariharan, India, Speech  
Ms. Paige Holmes, Canada, Speech

## J

Ms. Megan Janecka, Canada, Cleft Charity  
Leadership  
Mrs. Malka Jayathilake, Sri Lanka, Speech  
Ms. Horace Joelle, Madagascar, Surgery

## K

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Prof. Rajib Khadka, Nepal, Surgery  
Dr. Mohammad Khan, Bangladesh, Surgery  
Mrs. Elizabeth Khuzakhuza, Malawi, Manager  
Coordinator

## L

Ms. Lia Laranjeira, Brazil, Dental  
Dr. Twiggy Lazarte Hesse, Peru, Dental  
Dr. Maria del Rocio Lu Chang Say, Peru,  
Orthodontics

## M

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Dr. Carlos Marrodan, Argentina, Surgery  
Dr. Candy Marquez, Mexico, Speech  
Dr. Franck Masumbuko, DRC, Manager/  
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Dr. Karla Mayra Morán López, Mexico, Speech  
Dr. Felicity Mehendale, UK, Surgery  
Dr. Haline Miguel, Brazil, Speech  
Mrs. Inoka Mirihagalia Kankanamalage,  
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Mr. Donald Mlombwa, Malawi, Nursing  
Ms. Courtney Mollenhauer, Canada, Cleft  
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Dr. Bethel Mulugeta, Ethiopia, Nutrition  
Ms. Susana Munariz, Canada, Cleft Charity  
Leadership  
Prof. Muthu Murugan, India, Dental  
Dr. Namitha Mysore Hiriyanna, India, Surgery

## N

Prof. Roopa Nagarajan, India, Speech  
Ms. Hiba Najeeb, Canada, Speech  
Ms. Scarlett Norambuena, Chile, Speech

## O

Dr. Ifeoluwa Oketade, Nigeria, Surgery  
Ms. Amanda Oliveira, Brazil, Speech  
Dr. Adeola Olusanya, Nigeria, Surgery  
Dr. David Orr, Ireland, Surgery  
Ms. Camila Osorio, Colombia, Psychology  
Ms. Nana Owusu, Ghana, Speech

## P

Ms. Mirta Palomares, Chile, Speech  
Dr. Vikram Pandit, India, Surgery  
Dr. Sneha Patil, India, Dental  
Dr. Aruna Patri, India, Dental  
Dr. Rui Pereira, Brazil, Surgery  
Dr. Debolina Pramanick, India, Surgery  
Dr. Manu Prasad, India, Surgery  
Dr. Dushyant Prasad, India, Cleft Charity  
Leadership

## Q

Prof. Ghulam Qadir Fayyaz, Pakistan,  
Cleft Charity Leadership

## R

Ms. Jackie Riley, UK, Cleft Charity Leadership  
Mrs. Carolina Rivera, Costa Rica, Speech  
Prof. Nichola Rumsey, UK, Psychology

## S

Ms. Meghana S., India, Speech  
Dr. Ankita Saikia M., India, Research  
Dr. Debbie Sell, UK, Speech  
Ms. Varsha Shankar, India, ENT/Audiology  
Ms. Pamela Sheeran, USA, Cleft Charity  
Leadership  
Ms. Cari Siebrits, Canada, Cleft Charity  
Leadership  
Dr. Alicia Sigler, Mexico, Surgery  
Ms. Taylor Snodgrass, USA, Speech  
Ms. Isabella Speranza, Canada, Speech  
Ms. Swetha Sridhar, India, Speech  
Mrs. Manju Subrahmanian, India, Speech  
Ms. Maan Sukte, Myanmar, Speech  
Dr. Triona Sweeney, Ireland, Speech

## T

Mr. Amanuel Tafese, Ethiopia, Manager/  
Coordinator  
Ms. Sara Tesfaye, Ethiopia, Speech  
Dr. Shannon Theis, USA, Speech  
Dr. Cristiano Tonello, Brazil, Surgery  
Mrs. Silvia Torres Cavallo, Argentina, Dental  
Dr. Christian Tshisuz Nawej, DRC,  
Anesthesiology

## V

Dr. Radost Velikova, Bulgaria, Orthodontics  
Dr. Surabhi Vijaya Kumar, India, Surgery

## W

Ms. Rachel Winer, Canada, Cleft Charity  
Leadership

## Y

Ms. Phanomwan Yoodee, Thailand, Social Work

## Z

Dr. Ronald Zuker, Canada, Surgery



# Appendices

## CoCP Vaccine Equity Statement

Released: April 12, 2021

The Circle of Cleft Professionals (CoCP) is a coalition of the world's leading cleft lip and palate organizations. We work with thousands of health workers around the globe to support health outcomes for infants, children, and adults affected by cleft.

Worldwide, over 150,000 babies are born with cleft each year. These individuals need timely access to nutrition services, surgical care, oral health and orthodontic care, as well as speech therapy to prevent life-disability, morbidity, and premature death.

In a recent global study of cleft professionals in low and middle-income countries (LMICs), nearly 80% report a distressing decrease in the number of patients accessing critical cleft care due to the pandemic.

Though vaccines are now being distributed in more than 161 countries and territories across the world, vaccination has barely begun in the majority of LMICs.

We must prioritize rapid vaccination, beginning with health workers, to save lives and stop the transmission of the COVID-19 virus. With new variants emerging, vaccine equity is not only a moral imperative — it is a matter of global security and our shared future.

In this Year of the Health and Care Worker, we stand in solidarity with all suffering through the struggles of the pandemic. We are in complete support of the WHO's Vaccine Equity Declaration, and urge policymakers to prioritize health care professionals within national vaccine distribution to enable them to care for all patients and their communities safely.

### Join the CoCP

Apply for membership into the CoCP for future opportunities to connect with leaders in Comprehensive Cleft Care.

APPLY



# REFERENCES

## OPENING PLENARY

[Speech, Communication and Resilience \(SCR4Cleft\)](#)

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## SG1

[Solutions Group 1 'CCC Telehealth' Resources Library](#)

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## SG2

[Solutions Group 2 'Patient Outcomes' Resources Library](#)

[International Consortium for Health Outcomes Measurement \(ICHOM\). \(2018\). Cleft Lip and Palate Data Collection Reference Guide.](#)

[McLeod, S., Harrison, L. J., & McCormack, J. \(2012\). Intelligibility in Context Scale. Charles Sturt University.](#)

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## SG3

[Solutions Group 3 'CCC Protocols' Resources Library](#)

[Navia, A., Parada, L., Urbina, G., Vidal, C., & Morovic, C. G. \(2021\). Optimizing intraoral surgery video recording for residents' training during the COVID-19 pandemic: Comparison of 3 point of views using a GoPro. \*Journal of Plastic, Reconstructive & Aesthetic Surgery\*, 74\(5\).](#)

## SG4

[Solutions Group 4 'Parental Engagement' Resources Library](#)

[Smile Train \(1st Ed.\). \(2020\). 9 Reasons to Smile: Family Fun Activity Booklet. Smile Train.](#)

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## SG5

[Solutions Group 5 'CCC Telehealth – Spanish' Resources Library](#)

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## SG6

[Solutions Group 6 'Patient Outcomes – Spanish' Resources Library](#)



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