



circle
of cleft professionals



Solutions4CCC: Responding to COVID

Virtual Conference Report
September 17, 2020





Foreword

When faced with a vast and unprecedented challenge, what is in your toolkit? Comprehensive Cleft Care (CCC) professionals lean into creativity, embrace team insights, and always seek to learn and grow.

It shouldn't surprise us therefore, that 140 cleft professionals from over 30 countries recently animated an innovative forum toward caring for children and families affected by cleft amidst a global pandemic.

On behalf of the [Circle of Cleft Professionals](#) (CoCP) I'm delighted to introduce this snapshot of the [Solutions for Comprehensive Cleft Care: Responding to Covid](#) (S4CCC) conference.

With a huge debt to the [S4CCC International Advisors](#) for their insights and encouragement, the vision for an innovative online conference was established in June 2020: LMIC-rooted, learning nurturing, maximally interactive, and solution-focused.

An inspiring slate of global [panelists](#) prepared short Roundtable presentations, after which participants were guided by skilled [moderators](#) in engaging and collegial discussion, with technical support via NGO and Academic volunteers. Through pre-conference orientation sessions, as well as the conference day itself, we glimpsed the promise of a platform like [QiqoChat](#) for replicating some human elements of face-to-face conferences that we currently miss.

We're delighted to invite you to share S4CCC conference learning with colleagues via video recordings on the [CoCP YouTube channel](#). The insightful [opening](#) and [closing plenary](#) sessions provide a stirring overview of the challenges and opportunities of the current moment.

The intrepid S4CCC team humbly offers this report with hope that it will assist the global community of cleft professionals in cross-region and cross-NGO collaboration, research, encouragement, innovation and...solutions!

Hugh Brewster

On behalf of the **Circle of Cleft Professionals**



S4CCC Participants Worldwide

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Roundtable Topics



SOLUTIONS4CCC ROUNDTABLE 1A

Topic: CCC Outreach to Vulnerable Families
Moderated by: Dr. B. Subramanian

About the Roundtable

Reaching vulnerable families affected by cleft is a critical component of Comprehensive Cleft Care. How do we limit the number of children being left behind amidst the growing economic constraints of COVID? How do we address the growing backlog of patients requiring cleft care, especially for families with the fewest resources?



SOLUTIONS4CCC ROUNDTABLE 1B

Topic: Leveraging Technology for CCC
Team-Building and Patient Care
Moderated by: Dr. Debbie Sell

About the Roundtable

Multidisciplinary care requires effective communication between a variety of cleft professionals. During COVID, technology has helped maintain connections to our colleagues, as well as to further the care of support of families affected by cleft in new ways.

How are cleft teams in LMIC currently keeping connected, coordinated and learning? What innovative uses of technology are proving effective in achieving patient care outcomes? What are key constraints cleft teams in LMIC are facing when it comes to technology?



SOLUTIONS4CCC ROUNDTABLE 1C

Topic: Implementing and Monitoring
COVID Risk Management Procedures
Moderated by: Mr. Brian Sommerlad

About the Roundtable

The pandemic is challenging all of our "normal" routines when it comes to delivering Comprehensive Cleft Care. How are teams limiting the risks of exposing patients and professionals to COVID? What processes are teams using to determine what a "safe procedure" looks like? What elements of cleft care are considered too "risky" at this stage of the pandemic in your context?



SOLUTIONS4CCC ROUNDTABLE 1D

Topic: Caring for Your Team (and Yourself!)
during the Pandemic
Moderated by: Dr. Ruben Ayala

About the Roundtable

COVID takes a significant personal and professional toll on healthcare workers worldwide. As a result, equipping teams to work effectively and collaboratively in a virtual and high-stress environment is top of mind for CCC leaders. In this Roundtable, participants will share insights and strategies for maintaining team morale, promoting multidisciplinary team-based care virtually, and prioritizing self-care during the pandemic.



SOLUTIONS4CCC ROUNDTABLE 2A

Topic: A Path Forward for Safe, Timely Palate
Repairs
Moderated by: Dr. Ronald Zuker

About the Roundtable

Delayed cleft palate surgery can significantly alter the long-term treatment trajectory and health outcomes for a child born with cleft. In this Roundtable session, participants will discuss new protocols for carrying out safe palate surgeries, strategies for managing patient backlog and effective virtual/in-person approaches to pre- and post- surgery care.



SOLUTIONS4CCC ROUNDTABLE 2B

Topic: Promising Approaches to Speech
Therapy during COVID
Moderated by: Dr. Tim Bressmann

About the Roundtable

Speech therapy has been redefined in the COVID era, with speech professionals forced to work in new and innovative ways. In this Roundtable, participants will explore safe, promising approaches to virtual and in-person speech therapy, including online tools, parent engagement strategies, lessons learned and key outcomes.



SOLUTIONS4CCC ROUNDTABLE 2C

Topic: Resuming Safe In-Person Oral Health
Care Amidst the Pandemic
Moderated by: Dr. Marina Campodonico Frisch

About the Roundtable

Oral health professionals and patients are at a heightened risk of COVID due to exposure to respiratory aerosols. In this session, oral health care professionals will share risk mitigation strategies and new protocols for providing safe in-person NAM, dental and orthodontic treatment, as well as strategies for effective management of patient backlog.



SOLUTIONS4CCC ROUNDTABLE 2D

Topic: Newborn Nutrition and Social Support
at a Distance
Moderated by: Mr. Gareth Davies

About the Roundtable

COVID has disrupted the care pathway and support system in place for families newly affected by cleft lip and palate. Ensuring families feel equipped to navigate the CCC journey until regular CCC services can resume is critical to their physical and mental health. In this Roundtable, participants will share insights and strategies for effectively supporting families from a distance through nutrition assistance, counselling and psychosocial support.

S4CCC Roundtable 1A Summary: CCC Outreach for Vulnerable Families



September 17, 2020

Panelists	Dr. Mekonen Eshete	Ms. Saudha Nakandha	Dr. Maria del Carmen Pamplona
Moderator	Dr. B. Subramaniyan		
Roundtable Support	Ms. Courtney Mollenhauer	Ms. Allison Paul	Rev. Dr. Nan Hudson



Panelist: Dr. Mekonen Eshete, Ethiopia

CCC Outreach Approaches	COVID Challenges/Barriers
<ul style="list-style-type: none"> Ran a radio broadcast over 7 consecutive days promoting available services and the number to call for phone-based support Phone-based support: <ul style="list-style-type: none"> Called all active families to reassure them that support was still available Nutrition, oral hygiene and social counselling being provided by phone Parents being coached on how to provide speech support for children Referrals made when possible to local professionals Brochures distributed to maternal/childbirth departments of local hospitals and cleft sensitization training conducted for the departments' nurses/doctors Prioritizing most vulnerable cases for in-person care where travel is possible 	<ul style="list-style-type: none"> Access to transportation, reliable internet, electricity and phones is limited; travel costs have increased Families regularly change phone numbers Lack of adequate space/resources for tele-health support; families often living in small, crowded spaces Parental acceptance & comprehension limited without in-person contact/demonstrations, especially for illiterate caregivers



Panelist: Ms. Saudha Nakandha, Uganda

CCC Outreach Approaches	COVID Challenges/Barriers
<ul style="list-style-type: none"> Radio programs run in several languages promoting available care for new patients and feeding advice Branded t-shirts distributed to community ambassadors promoting available cleft care services Nutrition counselling provided by phone and nutrition take-away packages distributed to the most high-risk patients Transportation reimbursements increased for families to offset higher public transit costs (due to reduced vehicle capacity) 	<ul style="list-style-type: none"> 90% of cases require nutrition education/treatment Transportation restrictions and increased travel costs Community-based outreach programs on hold during lockdown



Panelist: Dr. Maria del Carmen Pamplona, Mexico

CCC Outreach Approaches	COVID Challenges/Barriers
<ul style="list-style-type: none"> A variety of mediums being used to provide structured tele-speech including storybook-reading, cooking, singing, writing, theatre and art <ul style="list-style-type: none"> Narrated stories and songs customized for each patient and shared through WhatsApp/email Group choirs being run through Zoom for four different age groups; songs chosen based on articulation targets Running a cell phone and tablet donation campaign to reach more families 	<ul style="list-style-type: none"> Poverty is a risk factor for speech, language, emotional and cognitive development Delayed speech therapy impacts speech and language outcomes

Key Themes from the Roundtable Discussion

Radio outreach

- While not the most targeted outreach method, radio can be very useful to reach families with limited connectivity/mobile phone access
- Suggestion to explore a **regular radio program** for families affected by cleft on its **own wavelength** and incorporating a theatre/story-telling component to disseminate messages on feeding, nutrition, speech etc.

Access to technology/internet

- Idea of providing **preloaded tablets** that do not require internet connection. These devices could be programmed to prevent other use
- Partnering with telecom companies to get sim cards or **phone credits** donated for the most vulnerable families
- Covering the cost of data (~1-2 hours/week) for families who cannot afford it, when possible
- For centres without access to laptops, **WhatsApp video** and **Zoom** work well on mobile phones for tele-speech or counselling
- Questions raised about how to leverage technology to provide support for areas that require regular hospital visits like NAM and ortho

Community-based outreach

- Expanding nutrition centres and running **training for nutritionists** at district hospitals so that at-risk babies have support closer to home
- Distribution of face masks and soap; community-based sensitization on hand-washing/**COVID prevention** for families affected by cleft
- Having a **centralized contact** so that healthcare workers at a grassroots level know who to contact when a child is born with cleft

Resuming in-person care safely

- Many families afraid to travel and visit hospitals; **phone-based counselling, transportation assistance** and **provision of PPE** may help address these concerns
- Prioritization of most vulnerable cases, particularly malnourished newborns

Coordinating outreach efforts

- Social worker/coordinator plays an important role linking all members of the team
- Important to understand how **different team members** are conducting virtual support so efforts/parental advice can be coordinated

Tele-Speech

- Incorporating **fun components** like storybooks, singing and play makes virtual speech therapy more engaging
- **Local celebrities** can be leveraged to help motivate families to participate in tele-speech and continue practicing at home
- Possibility of linking tele-speech efforts with **community-based mobilizers** (support with distribution of materials or facilitating sessions)

Resources Cited

- Smile Train's [*Speech Games and Practice*](#) mobile application

	Participant	Specialty	Country		Participant	Specialty	Country
1	Alexander Gross	NGO	Germany	2	Alicia Sigler	Surgery	Mexico
3	Anis Fathima K	Coordination	India	4	Ana Alarcón Arratia	Dental	Chile
5	Aparna VS	Speech	India	6	Anjali Kant	Speech	India
7	Bertha Tendo Kyozaire	Nutrition	Uganda	8	Benjamin Fomete	Surgery	Nigeria
9	Chimwemwe J Mvula	Coordination	Malawi	10	Dianne Erquiaga	NGO	Peru
11	Elizabeth Khuzakhuza	Coordination	Malawi	12	Fernando Henrique Almas Carvalho	Surgery	Brazil
13	Gareth Davies	NGO	France	14	George W. Galiwango	Surgery	Uganda
15	Ghulam Qadir Fayyaz	NGO	Pakistan	16	Godavarthi Sri Lakshmi	Speech	India
17	Hanna Abebe Håkonsen	Speech	Norway	18	Harish K	Surgery	India
19	Hugh Brewster	NGO	Canada	20	Jackie Elton	NGO	UK
21	Jackie Riley	NGO	UK	22	Julieta Perondi	Psychology	Argentina
23	Julio Pratesi	Surgery	Argentina	24	Malka Jayathilake	Speech	Sri Lanka
25	Manju Subrahmanian	Speech	India	26	Manu Prasad	Surgery	India
27	Maria del Rocio Lu Chang Say	Orthodontics	Peru	28	Maria Laura Martellotta	Speech	Argentina

29	Matt Fell	Surgery	UK	30	Meghana S	Speech	India
31	Miriam Nabie	Nutrition	Kenya	32	Melissa Antoneli	Speech	Brazil
33	Muhammad Anwar	Surgery	Pakistan	34	Morgan Bober	NGO	USA
35	Nana Akua Owusu	Speech	Ghana	36	Nati Getnet	Speech	Ethiopia
37	Neeti Daftari	NGO	Canada	38	Pamela Sheeran	NGO	USA
39	Per Hall	Surgery	UK	40	Phanomwan Yoodee	Social Work	Thailand
41	Rishabh Shah	Surgery	India	42	Ricardo Federico Merin	GP	Argentina
43	Sarah Hamilton	NGO	USA	44	Roopa Nagarajan	Speech	India
45	Seleman Mbaluku	Nursing	Malawi	46	Shannon Theis	Speech	USA
47	Shiferaw Berbirssa	Orthodontics	Ethiopia	48	Siddhartha Chatterjee	Surgery	India
49	Sonakshi Rawal	Speech	India	50	Swetha Sridhar	Speech	India



Click to watch Roundtable 1A Video

S4CCC Roundtable 1B Summary: Leveraging Technology for Team-Building & Patient Care

📅 September 17, 2020

Panelists	Dr. Usama Hamdan	Dr. Adeola Olusanya	Ms. Carolina Rivera Gutierrez
Moderator	Dr. Debbie Sell		
Roundtable Support	Ms. Sarah Hamilton	Ms. Grace Peters	



Panelist: Dr. Usama Hamdan, USA

Leveraging Technology Approaches	COVID Challenges/Barriers
<ul style="list-style-type: none"> • Telehealth / virtual support offered in: <ul style="list-style-type: none"> ○ Post-operative care, wound management, taping and surgical orthopedics ○ Nutrition and Psychosocial Support ○ Educational videos (e.g. speech therapy sessions, COVID Education) • Augmented Reality: <ul style="list-style-type: none"> ○ Allows remote communication - drawing on a 3-D environment in real time ○ On-site partners strengthen and reinforce their skills ○ U.S.-based GSF surgeons remotely assist & guide on-site colleagues during live lip repair surgery 	<ul style="list-style-type: none"> • Access to internet, speed of internet connection • Low quality patient photographic documentation by parents • Cancellation of Missions and uncertainty of future missions during COVID • Conversion of some cleft facilities to Covid-19 units • Affordability & availability of patient transportation



Panelist: Dr. Adeola Olusanya, Nigeria

Leveraging Technology Approaches	COVID Challenges/Barriers
<ul style="list-style-type: none"> • At least two specialists are now present at each clinic session since re-opening, with dedicated laptop for sending pictures/videos to other cleft specialists not on-site • Professional Development webinars viewed and discussed among the cleft team • Reduced the number of patient clinic visits by: <ul style="list-style-type: none"> ○ Dedicated phone number for re-scheduling of appointments without having to physically come to clinic ○ Encouraging submission of WhatsApp images and videos for review prior to clinic visit (e.g. speech sample) ○ Encouraging patients without smart devices to use neighbour or local vendor to submit info via WhatsApp ○ Scheduling video calls for follow up where appropriate • Modification of our alveolar molding plate (from avg of 8 visits to only 2) • Intubation aid to reduce number of intubation attempts • Speech Therapy device for distanced speech therapy 	<ul style="list-style-type: none"> • Computers not available to cleft team during shutdown • Computers not generally available for most families • Some families do not have access to smart devices



Panelist: Ms. Carolina Rivera Gutierrez, Costa Rica

Leveraging Technology Approaches	COVID Challenges/Barriers
Virtual Speech Therapy <ul style="list-style-type: none"> • Zoom - easy way to interact with parents and children • Interactive, engaging sessions are important • Parents are key, especially for young children Virtual Group Therapy (workshops) <ul style="list-style-type: none"> • Workshops for children and families alike • Interactivity and dynamic group sessions • Parent support and education 	<ul style="list-style-type: none"> • Patient/staff isolation and uncertainty amidst COVID • Low connectivity in some areas

Key Themes from the Roundtable Discussion
Technology/device availability <ul style="list-style-type: none"> • Many families without Wifi or data plan. National connectivity can be intermittent. • Only 1 computer or smartphone per family, if any at all. Potential to loan equipment particularly for speech therapy? Offer technology training for parents? Provide compensation to neighbours who share a device with a family? • WhatsApp is the most popular free app that provides video • Provide clinics via Zoom where feasible
Minimizing Patient In-Person Visits <ul style="list-style-type: none"> • NAM aligners, telehealth, written materials that support a telehealth approach • Amending the initial fit of the plate in pre-surgical orthopaedics to limit orthodontic visits • Costs of sending/sharing resources locally? Opportunity for NGO funding support? • Make virtual therapy sessions more interactive by using toys etc.; ask kids to listen to stories and practise articulation • Train parents to provide speech support at home and customize support for each family's situation/context
Telehealth <ul style="list-style-type: none"> • Enables patients and families to receive care quickly and efficiently • Local partners able to reach many patients (group sessions and individual sessions) • Limits the expense needed for COVID testing and PPE
CCC Centre Connectivity <ul style="list-style-type: none"> • NGOs should consider Wifi bandwidth a "core business" need for funding partnership • Loaning of phones with "pay as you go" plans with non-cleft care functions disabled to families in need • Access to computers and support with language training for resources not published in local language

CCC Professional Development

- How to further adapt **webinar model** for regional/situational needs, and in light of COVID constraints
- Danger of relying on hastily published COVID research that has not been fully vetted --- **quality control** helpful, and equipping local teams to assess and communicate relevant research internally/externally
- Equipping teams that rely on cleft missions to respond in the COVID era of no/limited international cleft missions

Research and Advocacy

- Equip local partners to advocate for CCC to local Ministries of Health/Finance, backed up by published research
- NGOs can sponsor training that is recognized by **local medical authorities**
- Ensure local CCC teams have access to **relevant research** (e.g. preferential ACPA rate?)
- Cleft is a niche concern, **importance of collaboration** and connection to wider concerns (e.g. safe surgery)

Resources Cited

- Tools that allow for distancing between the service provider and the patient ([e.g. Oral and Nasal Listener for nasal emission](#))
- [Sustainable Cleft Care: A Comprehensive Model Based on the GSF Experience](#)
- [Virtual NAM](#)
- Smile Train Speech pathology training course in South America
- [World Cleft Coalition publication](#)
- [Clinical and Economic Impact of Global Smile Foundation's Surgical Program](#)
- [Simulation-based Comprehensive Cleft Care Workshop](#)

	Participant	Specialty	Country		Participant	Specialty	Country
1	Ana Alarcón Arratia	Dental	Chile	2	Aparna VS	Speech	India
3	Benjamin Fomete	Surgery	Nigeria	4	Cornelius Masambu	Surgery	Uganda
5	Daniel Sseremba	Speech	Uganda	6	Dianne Erquiaga	NGO	Peru
7	Domenico Scopelliti	Surgery	Italy	8	Donald Mlombwa	Nursing	Malawi
9	George W. Galiwango	Surgery	Uganda	10	Dushyant Prasad	NGO	India
11	Felicity Mehendale	Surgery	UK	12	Fernando Almas Carvalho	Surgery	Brazil
13	Fikile Khangamwa	Nursing	Malawi	14	Foster Mbomuwa	Research	Malawi
15	Francis Tegete	Surgery	Tanzania	16	Gabriela Prearo	Speech	Brazil

17	Ghulam Qadir Fayyaz	NGO	Pakistan	18	Glendora Tremper	Speech	USA
19	Harish K	Surgery	India	20	Hedieh Hashemi Hosseinabad	Research	USA
21	Hugh Brewster	NGO	Canada	22	Inoka M Kankanamalage	Research	UK
23	Karen Goldschmied	Speech	Chile	24	Lucy Dodoli	Nursing	Malawi
25	Maan Sukte	Speech	Myanmar	26	Maimunat Alex-Adeomi	NGO	USA
27	Malka Jayathilake	Speech	Sri Lanka	28	Maria del Rocio Lu	Orthodontics	Peru
29	Matt Fell	Surgery	UK	30	Meghana S	Speech	India
31	Midori Hanayama	Speech	Brazil	32	Miriam Nabie	Nutrition	Kenya
33	Mirta Palomares	Speech	Chile	34	Neeti Daftari	NGO	Canada
35	Pamela Sheeran	NGO	USA	36	Praveen Ganesh Natarajan	Surgery	India
37	Manu Prasad S	Surgery	India	38	Puneet Batra	Orthodontics	India
39	Radost Velikova	Orthodontics	Bulgaria	40	Rishabh Shah	Surgery	India
41	Roopa Nagarajan	Speech	India	42	Serena Kassam	Orthodontics	Canada
43	Simone Fishbach	Speech	Canada	44	Swetha Sridhar	Speech	India
45	Tim Bressmann	Speech	Canada	46	Varsha Shankar	Audiology	India
47	Vignesh Kailasam	Orthodontics	India				



Click to watch Roundtable 1B Video

S4CCC Roundtable 1C Summary: Implementing & Monitoring COVID Risk Management Procedures

 September 17, 2020

Panelists	Dr. Carolina Cramaro	Prof. Youri Anastassov	Dr. Zipporah Gathuya
Moderator	Mr. Brian Sommerlad		
Roundtable Support	Ms. Rachel Winer		Ms. Christine Muscat



Panelist: Dr. Carolina Cramaro, Argentina

Risk Management Strategies	COVID Challenges/Barriers
<ul style="list-style-type: none"> • Use a pre-surgical isolation room for patients • Minimize number of individuals who are in an operating room • Provide transportation to/from hospital for patients to minimize risk of exposure • Provide telemedicine from hospital • Reach out via WhatsApp and social media to minimize in-person contact 	<ul style="list-style-type: none"> • As human beings, we are social and need touch and human contact: face to face contact is still important! • Not all patients have access to internet and smartphones • Burden of care for CCC providers is increasing during COVID



Panelist: Prof. Youri Anastassov, Bulgaria

Risk Management Strategies	COVID Challenges/Barriers
<ul style="list-style-type: none"> • Facilitate CCC team meetings via Zoom, maintain social distancing • Locally developed Electronic Medical Records platform (EMFRA) connects parents with CCC team (Surgeons, ENT, SLP, Orthodontists, Feeding Nurses) • Parents send in many more pictures and videos during pandemic • Extend reach of EMFRA to patients via apps like Viber and WhatsApp • Working towards training parents to provide speech therapy at home 	<ul style="list-style-type: none"> • Hospitals are incentivized to continue procedures in order to meet profit-making targets • Inconsistent rules about which patients require COVID testing • CCC teams may not work independently from government approaches • Patients are influenced by inaccurate reports about COVID in the media



Panelist: Dr. Zipporah Gathuya, Kenya

Risk Management Strategies	COVID Challenges/Barriers
<ul style="list-style-type: none"> • Provide telemedicine via phone and WhatsApp. Patients are able to ask for advice via phone, but limited regarding other support • Adapt to local comfort and local circumstances, including availability of PPE 	<ul style="list-style-type: none"> • Perception that cleft patients were receiving better care than other patients because of international partnerships (better PPE?)

<ul style="list-style-type: none"> Continue progress toward online medical records, spurred on by COVID Create clear guidelines about which procedures will resume and which will be postponed 	<ul style="list-style-type: none"> Patients with pre-existing conditions were not getting care and immunizations for children were not continued Internet access is not universal; not everyone has a cell phone CCC professionals drawn away from cleft care to provide COVID care
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Key Themes from the Roundtable Discussion

Enhancing Risk Management

- Routine COVID testing** for cleft patients is not standard in all contexts -- any symptoms leads to delays in all treatment
- How to reduce the risk of infection in in-person speech therapy sessions where the child is not wearing a mask
 - 2-meter rule**, opening windows, elements of treatment that can be delivered at a distance
- Some patients are not pursuing treatment because of potential exposure to infection during transportation to hospital, others because of increased costs of transportations (longer hospital stay also increases living costs for family in hospital neighbourhood)

Training for CCC Team Members on Infection Control

- Need consistent, timely, orientation and **team-based training** for everyone interacting with cleft patients
 - Mode of transmission, minimizing risk procedures, appropriate selection/use of PPE
- Evidence that nurses are most at risk of infection and spread as they spend most time with patients
- Team-based **communication and planning** critical to try to keep everyone safe

COVID Testing

- Inconsistent access to COVID testing for patients
- Testing procedures can lead to **longer hospital stays** & required to **isolate post-surgery**
- False negative tests a significant concern, can't rely only on test results and must treat patients as potentially COVID positive
- Over-emphasis on testing vs. equipping parents to try to keep patients safe

CCC Professional PPE Strategies

- Still learning **new processes** for keeping anesthesiologists, surgeon, patients safe
- Some find N95 masks very uncomfortable, face shields can make vision more difficult due to light reflection, use of microscopes for palate repairs, loupes glasses and masks for lip repairs
- How to manage risk of aerosol spread a concern especially with intubation, suction, difficult airway

Resources Cited

- [Speech@Home](#): Parent-led speech therapy
- [Electronic Medical Records for Facial Anomalies \(EMFRA\)](#): Bulgarian, interactive medical record platform

	Participant	Specialty	Country		Participant	Specialty	Country
1	Adelaide Gyamera	Speech	Ghana		Ana Alarcon Arratia	Surgery	Chile
3	Bryan Thompson	Orthodontics	Canada		Carla Florin	Surgery	Chile
5	Dickson Mwenitete	Nursing	Malawi		Edwin Cosalan	Surgery	Philippines
7	George Galiwango	Surgery	Uganda		Karen Wong	Surgery	Canada
9	Luqman Majid	Surgery	Iraq		Melissa Antoneli	Speech	Brazil
11	Mohammad Khan	Surgery	Bangladesh		Nargis Jahan	Speech	Bangladesh
13	Radost Velikova	Orthodontics	Bulgaria		Ronald Zuker	Surgery	Canada
15	Taweni Chiumia	Nursing	Malawi		Vikram Pandit	Surgery	India



Click to watch Roundtable 1C Video

S4CCC Roundtable 1D Summary: Caring for your Team (and Yourself!) during the Pandemic

📅 September 17, 2020

Panelists	Dr. Jayanth B.S.	Dr. Carmen Gloria Morovic	Dr. Opoku Ampomah
Moderator	Dr. Ruben Ayala		
Roundtable Support	Mr. Abdon Aguillon	Ms. Beyhan Annan	



Panelist: Dr. Jayanth BS, India

Demonstrating Care Strategies	COVID Challenges/Barriers
<ul style="list-style-type: none"> Prioritize regular team meetings and pro-active communication Attend online webinars, engage with research literature Schedule staff to work in-person on alternating weeks, quarantine when needed, reassure team members, regular COVID testing, safety vigilance Contribute to hospital triage protocols Focus upon online SLP and modified NAM protocols Self-care: take hobbies seriously, sleep properly, eat well, 5-minute daily debrief, prioritize your mental & physical health Celebrate how CCC teams are built to adapt <i>Let's have a heart bigger than its size</i> 	<ul style="list-style-type: none"> Uncertain time with lots of emotion - a lot of fear, lack of motivation is a challenge Patient lack of smartphones and poor internet connectivity a challenge to home-based therapy



Panelist: Dr. Carmen Gloria Morovic, Chile

Demonstrating Care Strategies	COVID Challenges/Barriers
<ul style="list-style-type: none"> Patients have mandatory 1 week quarantine + pre-surgical questionnaire + a negative PCR COVID exam 24-48 hours before surgery Team checked daily and all given sufficient PPE to feel reassured and safe N95 Mask + Running Mask + Eye Protectors + Glasses + Loupes + Facial Mask for surgery Training residents through a Go Pro Hero 7 Black Camera, handheld by an assistant surgeon 	<ul style="list-style-type: none"> If any positive responses to pre-surgical questionnaire, surgery is delayed by a minimum of 14 days Restricted attendance and shortened surgical time in the OR is a challenge for teaching



Panelist: Dr. Opoku Ampomah, Ghana

Demonstrating Care Strategies	COVID Challenges/Barriers
<ul style="list-style-type: none"> Work with NGOs to get appropriate PPE and screen everyone before entering the facility Design staff support systems with open lines of communication that promote a team-based approach to CCC and check-up on one another often 	<ul style="list-style-type: none"> Health systems are not as robust as in High Income Countries Low Availability of PPE. E.g. increase price of box of gloves from \$3 USD → \$70 USD.

- **Self Care:** lead by example as an **ambassador to the "new-normal"**, pray and meditate, read uplifting material, **stay connected** with family, engage with a new **hobby**, **channel fear** into constructive action
- *As a leader, do not ask people to do something you wouldn't do*
- A lot of anxiety, fear of infection, fear of coming to work, poor public education
- Availability of testing & delays in results for testing, fear of 2nd wave of infection

Key Themes from the Roundtable Discussion

Lack of support from local health authorities

- Poor public education about COVID
- Not every health professional following the same precautions and protocols
- Expense of PPE and engagement with the private sector
- Insufficient compensation packages for staff/family during COVID

Community COVID Costs

- Increase in poverty in vulnerable communities as parents lose jobs and remove their children from school
- Patients can feel disconnected and abandoned

Impact on CCC Strategy

- Teams have to consider this a long-term challenge, not a short-term disruption and plan accordingly to address this social problem
- Access to food may be more pressing concern than surgery and psychosocial care may take precedence over SLP therapy
- CCC **volunteers** also need support and communication at this time

Self-Care and Resilience Support

- Promote self-care and mental resilience on the team
- Meditation and yoga can be helpful practices

Resources Cited

- [Quick Coherence Meditation Technique](#)

	Participant	Specialty	Country		Participant	Specialty	Country
1	Alexander Gross	NGO	Germany	2	Anna Arijaona	Dental	Madagascar
3	Dianne Erquiaga	NGO	Peru	4	Dushyant Prasad	NGO	India
5	Karen Goldschmied	Speech	Chile	6	Mamy Ramamonjisoa	NGO	Madagascar
7	Nana Akua Owusu	Speech	Ghana	8	Neeti Rajagopalan	Surgery	India
9	Siddhartha Chatterjee	Surgery	India	10	Silvia Torres Cavallo	Dental	Argentina
11	Tingo Chipanda	Anesthesiology	Malawi				



Click to watch Roundtable 1D Video

S4CCC Roundtable 2A Summary: A Path Forward for Safe, Timely Palate Repairs

 September 17, 2020

Panelists	Dr. George W. Galiwango	Dr. Carla Florin	Dr. Siddhartha Chatterjee
Moderator	Dr. Ronald Zuker		
Roundtable Support	Ms. Courtney Mollenhauer	Ms. Raman Jhalli	



Panelist: Dr. George W. Galiwango, Uganda

Safe, Timely Surgery Approaches	COVID Challenges/Barriers
<ul style="list-style-type: none"> • Pre-surgery follow up/nutrition support <ul style="list-style-type: none"> ○ Conduct phone-based follow up and increase transportation reimbursements ○ Distribute food packages for high risk patients (lasts 2-3 days) ○ Increased nutrition education during hospital visits ○ Host radio talk show to educate families about cleft patient nutrition/feeding • Prioritize patients under 5 with cleft palate for nutrition support and surgery • Introduce new protocols for resuming safe surgery including a strict pre-admission checklist, vigilance in the surgical ward, pre-anaesthetic assessments and use of PPE during anaesthesia, surgery and recovery 	<ul style="list-style-type: none"> • Travel restrictions and increased cost of transportation • Reduced access to health facilities, outpatient visits and surgery • Infant malnutrition increased as affordability of food decreased • Anxiety/fear among both hospital staff and families affected by cleft



Panelist: Dr. Carla Florin, Chile

Safe, Timely Surgery Approaches	COVID Challenges/Barriers
<ul style="list-style-type: none"> • COVID Committee formed to assess information and shape new safety protocols • Pre-surgery protocols: pre-surgery COVID test and blood samples, 2 weeks pre-surgical isolation for the patient and caregiver and a COVID questionnaire conducted by phone • Surgical protocols: restricted to 2 procedures/day, consent forms collected, anaesthetist and surgeon evaluation conducted and careful use/removal of PPE • Post-surgery protocols: 48hr + 7 day evaluation conducted by nurse and 10 day post-op assessment conducted by surgeon virtually (standard protocols reduced) 	<ul style="list-style-type: none"> • Establishing new protocols, especially as COVID information changed daily • Shortage and high cost of necessary equipment & PPE



Panelist: Dr. Siddhartha Chatterjee, India

Safe, Timely Surgery Approaches	COVID Challenges/Barriers
<ul style="list-style-type: none"> • Pre-surgery protocols: mandatory COVID testing for all patients, use of PPE and face shield in surgical ward, antibody testing for healthcare professionals • Surgical protocols: 3M and Sighematsu respiratory masks, high power vacuum suction and betadine solution to clean the oral cavity used during surgery; cautious use of cautery machine • Post-surgery protocols: online post-op assessment and patient follow up conducted with WhatsApp video 	<ul style="list-style-type: none"> • Challenges for team: increased cost/surgery, maintaining separate wards for cleft patients, cost/logistics to conduct COVID tests for all patients and risk of COVID exposure • Challenges for families: travel restrictions, fear of travel, undernutrition

Key Themes from Roundtable Discussion
<p>Surgical preparation (nutrition/transport)</p> <ul style="list-style-type: none"> • Nutrition outreach/support is critical; many surgeries being further delayed due to underweight or malnourished patients • Transportation support may need to be increased as cost of public transit has increased in many contexts due to vehicle capacity restrictions • Sourcing funding for nutrition support and travel assistance has been a constraint for many centres • Organizing a small bus or ambulance to transport families in key districts was one idea to help combat families' fear of using public transit
<p>Prioritizing cleft interventions (readiness, facilities)</p> <ul style="list-style-type: none"> • Prioritizing 'elective' cleft repair surgeries in general hospitals with many competing priorities for space/resources has been a challenge; private/cleft specialty institutions have had more flexibility to prioritize cleft surgery • Balancing the risk of bringing a child to the hospital vs. a delayed primary surgery and communicating this risk to families are key • CCC centres have determined different age thresholds for prioritization of cleft palate cases (15-18 months in some cases) • Addressing the backlog of primary cleft cases and determining how/when to manage adult patients are key questions for many teams
<p>Pre-operative evaluations</p> <ul style="list-style-type: none"> • Some centres encouraging the caregiver/patient to self-isolate for 10-14 days prior to surgery • Consensus that pre-surgery COVID testing is critical but not possible in some contexts due to cost, availability of testing kits and the wait time • Accommodation assistance needed for some vulnerable families as they await the results of the patients COVID test • Many centres have introduced consent waivers for caregivers in case of exposure to COVID
<p>Safe surgery</p> <ul style="list-style-type: none"> • Potential to re-use PPE in some cases if safety protocols are followed • Importance of managing the concerns of all healthcare professionals involved in the Operating Room • Higher cost per patient for surgery due to new safety standards and PPE requirements

- In some contexts, centres have used this time where new incoming cases are reduced to address backlog

Post-operative care & CCC follow up

- Many centres conducting virtual post-op care
- Research suggests that adults who undergo surgery while COVID-positive are at a higher risk than children of post-surgery complications
- Understanding the COVID-related challenges faced by other CCC disciplines and working as a team rather than in a fragmented manner

Resources Cited

- Study evaluating the **impact of COVID on cleft surgery** underway in the UK (with potential to broaden scale). Interested parties can reach out to Felicity Mehendale at felicity.mehendale@ed.ac.uk

	Participant	Specialty	Country		Participant	Specialty	Country
1	Alexander Gross	NGO	Germany	2	Alicia Sigler	Surgery	Mexico
3	Amit Basannavar	Surgery	India	4	Ana Alarcón Arratia	Dental	Chile
5	Anis Fathima K	Coordination	India	6	Benjamin Fomete	Surgery	Nigeria
7	Bertha Tendo Kyozaire	Nutrition	Uganda	8	Beyhan Annan	NGO	Lebanon
9	Brian Sommerlad	Surgery	UK	10	Bryan Thompson	Orthodontics	Canada
11	Charan Reddy	Surgery	India	12	Cornelius Masambu	Surgery	Uganda
13	Donald Mlombwa	Nursing	Malawi	14	Dickson Mwenitete	Nursing	Malawi
15	Edwin Cosalan	Surgery	Philippines	16	Dushyant Prasad	NGO	India
17	Felicity Mehendale	Surgery	UK	18	Elizabeth Khuzakhuza	Coordination	Malawi
19	Ghulam Qadir Fayyaz	NGO	Pakistan	20	Francis Tegete	Surgery	Tanzania
21	Hugh Brewster	NGO	Canada	22	Harish K	Surgery	India
23	Julio Pratesi	Surgery	Argentina	24	Jayanth BS	Surgery	India
25	Luqman Majid	Surgery	Iraq	26	Karen Wong	Surgery	Canada
27	Matt Fell	Surgery	UK	28	Maimunat Alex-Adeomi	NGO	USA
29	Mohammad Khan	Surgery	Bangladesh	30	Mekonen Abebe	Surgery	Ethiopia
31	Muhammad Anwar	Surgery	Pakistan	32	Manu Prasad	Surgery	India
33	Naomi Kekisa	Surgery	Uganda	34	Per Hall	Surgery	UK
35	Opoku Ampomah	Surgery	Ghana	36	Sarah Hamilton	NGO	USA

37	Taweni Chiumia	Nursing	Malawi	38	Shibani Das	Surgery	India
39	Tingo Chipanda	Anesthesia	Malawi	40	Tesfaye Mulat	Surgery	Ethiopia
41	Vikram Pandit	Surgery	India	42	Varun Menon P	Surgery	India
43	Youri Anastassov	Surgery	Bulgaria				



Click to watch Roundtable 2A Video

S4CCC Roundtable 2B Summary: Promising Approaches to Speech Therapy during COVID

📅 September 17, 2020

Panelists	Mrs. Lakshmi Godavarthi	Ms. Mirta Palomares	Ms. Nana Akua Owusu
Moderator	Dr. Tim Bressmann		
Roundtable Support	Ms. Ariana Gould	Ms. Bridget Lively	Ms. Pamela Sheeran



Panelist: Mrs. Lakshmi Godavarthi, India

Promising Approaches	COVID Challenges/Barriers
<ul style="list-style-type: none"> For virtual care, give explicit instructions to patients on how to sit, ensure good lighting, and how to record themselves for strong audio Advise use of common household objects in place of therapy materials for at-home sessions Give virtual high-fives as and hold hands up to the screen Send patients photos to demonstrate proper use of objects Use a table and chair vs. chairs with cushions to promote good posture. Instruct parents to check jaw movement and to apply oil for upper lip stretch so their finger slips off when too much pressure applied 	<ul style="list-style-type: none"> Some normal practices difficult to adapt to computer screen Patients initially avoided use of gadgets, unfamiliar to them Not possible to use typical therapy material (e.g. face formers, u trainers) Voice clarity sometimes requires patients to record themselves multiple times Challenging for patients to understand at-home exercises including bad posture (instructed to switch from cushioned beds to table chairs) and tongue and jaw movement (parent instructed to help), Some patients reluctant to make time for at-home therapy



Panelist: Ms. Mirta Palomares, Chile

Promising Approaches	COVID Challenges/Barriers
<ul style="list-style-type: none"> Opportunity for greater involvement and empowerment of parents in their children's treatment Invite patients and providers to view online training videos (e.g. Smile Train sponsored). Most popular topics are s & p sounds and compensatory articulation. Regional online instruction and collaboration an asset during COVID Continue to design audiovisuals/media so that parents can support their children from home Enable families to scan a QR code that brings them to an app with YouTube videos and hard copies of activities (e.g. Smile Train's training materials) 	<ul style="list-style-type: none"> Long closures of clinic due to COVID restrictions Virtual Care is a total change in the way SLPs care for patients of all ages and families: minimal resources available and increased donor support required New activities and strategies require constant assessment and re-evaluation for impact Many families have limited access to desktop computers but do have access to telephones and the internet



Panelist: Ms. Nana Akua Owusu, Ghana

Promising Approaches	COVID Challenges/Barriers
<ul style="list-style-type: none"> Promote parent involvement and control, which shifts the role of therapists vs. family support Many families prefer online support versus 1:1 sessions during COVID Online support allows for reactive sessions, lowers travel time/cost and promotes development of new skills 	<ul style="list-style-type: none"> Therapists lose some control over virtual sessions and there is stress upon relationship with families Therapists lose income during lockdown Cost of data, unstable internet and the further marginalization of the vulnerable key challenges as patients don't have smartphones Training therapists in adapting to new ways of working, as well as increased preparatory time part of the new reality Inability to use traditional toys/tools virtually a challenge

Key Themes from the Roundtable Discussion

Parental Acceptance of Telehealth

- Telehealth has opened up access to speech therapy for patients who otherwise would **not have had any access** previously in South America
- Fear of COVID infection** is driving acceptance of telehealth for some families, for others technological solutions are not appealing, or prefer that a therapist comes to the home
- Some assessments and **diagnosis** cannot currently be effectively done by telehealth, requires **face to face**
- Especially when **funding for transportation** and meals is provided, some families will choose face to face therapy over telehealth
- Cost of data and devices** is a huge barrier. Soliciting charitable discount from suppliers / NGO support fruitful to explore
- For many families, speech therapy needs pale in comparison to **no jobs, no social support, no strategies** for having children always at home

VPD and Synchronous vs. asynchronous perceptual and acoustic assessments

- Patients can't **access specialized tools** (e.g. nasendoscopy) via telehealth, without face to face therapy the backlog will increase
- For assessments, send the patients' materials beforehand, explain how important it is to speak clearly into the microphone. Patients **record themselves** and send the file, which is then used for assessment.
- Audio compression** is used in many phones. This can distort the signal. Also, consider tools such as the [WASP online signal processing website](#)

Training Parents and Colleagues

- Some therapists **fear** telemedicine
- Training of therapists** in how to do teletherapy is critical, not a simple task
- Families need to be prepared to discover how difficult it is to deliver therapy at home -- power cuts / loss of WIFI and prioritization of school over therapy can pose challenges
- Fun and engaging videos** that children and colleagues can watch over and over is a helpful strategy

- Parents of younger children should expect to **do activities with their children**, but hard for many to prioritize the time during the pandemic

Masks

- New washable masks** that include a **mouth window** are critical to transmitting visual information to patients during in-person sessions
- Research project: **which masks and face shields work best** for therapy sessions?

Resources Cited

- [WASP Online Speech Analysis](#)
- [Fundacion Gantz Speech Training Youtube Channel](#)

	Participant	Specialty	Country		Participant	Specialty	Country
1	Adelaide Emma Gyamera	Speech	Ghana	2	Adeola Olusanya	Surgery	Nigeria
3	Anjali Kant	Speech	India	4	Aparna VS	Speech	India
5	Carmen Gloria Morovic	Surgery	Chile	6	Carolina Gutierrez	Speech	Chile
7	Carolina Rivera	Speech	Costa Rica	8	Christine Muscat	Speech	Canada
9	Debbie Sell	Speech	UK	10	Dianne Erquiaga	NGO	Peru
11	Elizabeth Khuzakhuza	NGO	Malawi	12	Gabriela Prearo	Speech	Brazil
13	Glendora Tremper	Speech	USA	14	Hanna Abebe Hakonsen	Speech	Ethiopia
15	Hedieh Hashem	Speech	USA	16	Inoka Mirihagalla	Speech	Sri Lanka
17	Jackie Elton	NGO	UK	18	Lucy Dodoli	Speech	Malawi
19	Manju Subrahmanian	Speech	India	20	Maria del Carmen Pamplona	Speech	Mexico
21	Melissa Antoneli	Speech	Brazil	22	Midori Hanayama	Speech	Brazil
23	Nang Ei Ei Phyu	Social	Myanmar	24	Nargis Jahan	Speech	Bangladesh
25	Roopa Nagarajan	Speech	India	26	Shannon Theis	Speech	USA
27	Simone Fischbach	Speech	Canada	28	Sonakshi Rawal	Speech	India
29	Subramaniyan B.	Speech	India	30	Swetha Sridhar	Speech	India
31	Triona Sweeney	Speech	Ireland	32	Varsha Shankhar	Speech	India
33	Youri Anastassov	Surgery	Bulgaria				



Click to watch Roundtable 2B Video

S4CCC Roundtable 2C Summary: Resuming Safe In-Person Oral Health Care Amidst the Pandemic

📅 September 17, 2020

Panelists	Dr. Maria del Rocio Lu	Dr. Radost Velikova	Dr. Puneet Batra
Moderator	Dr. Marina Campodonico Frisch		
Roundtable Support	Mr. Abdon Aguillon		Dr. Serena Kassam



Panelist: Dr. Maria del Rocio Lu, Peru

Oral Health Care Strategies	COVID Challenges/Barriers
<ul style="list-style-type: none"> • Provide telehealth consultation remotely • Train NAM providers online for patients living outside the capital • Adapt face-to-face protocols from international guidelines in light of guidance from official health authorities • Initiate an oral health promotion program in light of backlog of cases 	<ul style="list-style-type: none"> • Heavy financial and economic impact of COVID upon the economy • Patients struggle to travel to hospital safely (re: public transportation) • Clinics still closed in light of high number of cases in Peru



Panelist: Dr. Radost Velikova, Bulgaria

Oral Health Care Strategies	COVID Challenges/Barriers
<ul style="list-style-type: none"> • Maintain Cleft team meetings • Enable In person consultation vs telehealth (patient preferences) • Use PPE in office (face shield, mask, gown, gloves) • Pre-treat patients with anti-microbial mouth rinse • Limit number of appointments in the day, minimize waiting room occupancy (including those accompanying patients) • Triage emergencies vs emergent cases • Consult with new patients via telehealth • Maintain EMR (electronic medical record), this is even more important as patients can upload info and ask questions etc virtually • Use UV Lamp in waiting room for disinfection and air flow • Initiate regular communication between patient and providers to alleviate stress and anxiety 	<ul style="list-style-type: none"> • Backlog management is challenging • Travel restrictions for patients and providers must be taken into account • More time required to organize patient records, cleft specialists, improve protocols



Panelist: Dr. Puneet Batra, India

Oral Health Care Strategies	COVID Challenges/Barriers
<ul style="list-style-type: none"> • Phone screening of patients for patient selection (e.g. emergency vs. elective cases) via meNT score • Implement clear treatment protocols, screen and sanitize patients at reception • Maintain HEPA air filtration, employ separate rooms for patients, negative pressure rooms where warranted • Monitor local COVID curve • Employ appropriate PPE at every stage • Modify NAM process to use NAM aligners, and dynacleft /nasal elevator, make appliance adjustments in a separate lab • Wax for nasal stent stabilization if surgery is deferred • Display chart for emergency vs follow-up ortho care • Reduce force or screw tension for orthodontic appliances, if patients are not coming for follow up • Defer orthognathic surgery as this is not emergency, broken wires or dislodged appliances would qualify as an emergency • Declutter patients, follow up such as quad helix vs RPE 	<ul style="list-style-type: none"> • Use of technology for teledentistry is a key challenge • Discerning which patients qualify as "emergency" critical • Continue to update protocols as COVID situation changes

Key Themes from the Roundtable Discussion

Transportation Challenges

- Safe transportation for patients and providers to hospitals/clinics a major concern: masks/shields, **additional costs**
- Patients may require **official authorization** from provider to allow patients to travel to come to clinic
- **Mailing supplies** to patients (for extra supplies needed) is a possible strategy
- **Triage** of patients based on urgency and timing is critical (e.g. bone graft, expansion, pre-surgical orthodontics vs pre-surgical orthopedics, orthognathic cases etc.)
- Inconsistent access to telehealth and virtual care (due to **connectivity and costs**) leads to early face to face re-opening

Patient and Provider Education

- Top priority is to **educate families** on triage priorities and rationale, **reassure** them that intention is best outcomes and the safety for their child, clearly communicate availability for **telehealth** visits and follow-up
- **Poor oral hygiene** will increase emergency cases, oral health education via telehealth should be expanded
- **Train local dentists** to do patient follow-up where travel is a concern, **educate community health workers** for ongoing patient support
- Ensure that oral health instruction is included in overall CCC telehealth approach, even if delivered by **non oral health professional** (e.g. nurse, nutritionist)
- Wrestle with how to provide some sort of care to **patients "in the middle"** (non-emergency)
- Risk of COVID has made many patients opt to **stay home** versus coming in for medical or dental appointments. Some patients have **incorrect information** about COVID risks.

- **Create new tools** to reach patients who do not have access to technology to access support

COVID Costs and Backlog

- **Expense of supplies and scarcity of proper PPE** is limiting patient treatment to emergencies only, increasing patient backlog
- Fewer and longer appointments each day (due to safety protocols) increases overall costs and contributes to **backlog**

Orthodontic Tips

- Explore use of Hypochlorite acid with **disinfection**, soak appliances in glutaraldehyde prior to adjusting
- Educate community health workers who can support professionals at a distance in critical situations, but also on a daily basis.
- Use nasal elevator / dynacleft to minimize visits during pre-surgical NAM, or aligners (where available)
- Adjust **air filters** to address aerosols is a top concern
- If appliances trap more bacteria etc., do the **risks outweigh the benefits?**
- **Prioritize pre-bone graft treatment**, when expansion needed, to not miss the critical time window

Resources Cited

- [Circle of Cleft Professionals](#) website
- [Smile Train](#) resources

	Participant	Specialty	Country		Participant	Specialty	Country
1	Anna Arikaona	Dental	Madagascar	2	Jayanth BS	Surgery	India
3	Mich Rakotomala	NGO	Madagascar	4	Nadia Raharinirina	NGO	Madagascar
5	Ricardo Federico Merin	Dental	Argentina	6	Shiferaw Degu	Orthodontics	Ethiopia
7	Silvia Torres Cavallo	Dental	Argentina	8	Vignesh Kailasam	Orthodontics	India
9	Youri Anastassov	Surgery	Bulgaria				



Click to watch Roundtable 2C Video

S4CCC Roundtable 2D Summary: Newborn Nutrition and Social Support at a Distance

📅 September 17, 2020

Panelists	Ms. Phanomwan Yoodee	Ms. Miriam Nabie
Moderator	Mr. Gareth Davies	
Roundtable Support	Ms. Morgan Bober	Mr. John Paul Lopez



Panelist: Ms. Phanomwan Yoodee, Thailand

Nutrition & Social Support Strategies	COVID Challenges/Barriers
<p>Role of Social Workers during COVID:</p> <ul style="list-style-type: none"> • Decrease parental worries and fears about COVID transmission through education and to facilitate access to CCC treatment • Mobilize available resources and expertise to fill gaps in care • Offer Tele-health psychosocial counselling through Facebook, Group LINE (mobile app) and one-on-one video counselling • Support nutrition and physical activities for patients • Solicit donations for facemasks/face shields for hospitals, local public health centres and cleft families • Stay connected with your CCC team remotely through technology such as Group LINE and video calls 	<ul style="list-style-type: none"> • Some patients believe false information about COVID transmission and social/physical distancing • COVID treatment priority puts hospital-based cleft treatments on hold • Shortage of PPE and increased prices • Second wave fears continue to delay hospital-based care resumption • Neighbouring borders remain closed increasing the need for supplementary nutrition and cleft care



Panelist: Ms. Miriam Nabie, Kenya

Nutrition & Social Support Strategies	COVID Challenges/Barriers
<ul style="list-style-type: none"> • Malnutrition in CLP infants causes nutrient deficiencies, slow growth, under-weight or height and poor surgical outcomes • Continue to accept new referrals in person, following WHO guidelines • Provide nutrition booklets to new mothers • Assess client nutritional health to inform planning for future care and to determine what staff resources will be needed (e.g. in-person or tele-health) • Follow-up care via phone call support for stable children with normal nutritional status • Cover costs for travel for at-risk cases to visit the clinic for in-person follow-up visits • Train Community Health Volunteers to make home visits • Encourage mothers to visit nearby health centres for growth and progress monitoring as needed 	<ul style="list-style-type: none"> • Support and play group activities have been put on hold to prevent the spread of COVID • Some patients do not have access to phones for tele-health • Families may not have funds to travel or provide for the nutritional needs of CLP infants

Key Themes from the Roundtable Discussion

Connection via Technology

- Critical for new mothers and families to be referred (via phone or virtually) to a cleft clinic and receive nutritional information
- **Telehealth** options provide care remotely when travel is impossible
- Stay connected to CCC teams remotely using technology
- Share information at a distance to prevent the spread of COVID; **keep information simple**
- WhatsApp groups (or similar) connect families to share information, support and experiences

Future Planning

- Plan for how you will continue to access these nutrition/social support resources should borders remain closed, trade limited, or governments call for a lockdown
- Send **food packages by mail** to families who cannot travel to access the nutritional goods they need and track their nutritional progress

Stigmatization of Health Care Workers

- To counter negative community perceptions of health care workers, demonstrate a firm commitment to wearing appropriate PPE
- Share **accurate information** to counter false ideas about the spread of COVID

Satellite Centres

- Consider opening smaller **satellite CCC centres** to provide limited in-person services when transportation is difficult
- Create isolated intake procedures and institute COVID testing to prevent spread
- **Proactive outreach** to families who may be more restricted than ever in their travel due to loss of income, travel restrictions, or fear of transmission
- Continue to reach out to vulnerable communities and offer support

Resources Cited

- [Early Care Training Programme](#) (also available in Spanish)

	Participant	Specialty	Country		Participant	Specialty	Country
1	Allison Winter Paul	Speech	Canada	2	Mohammad Khan	Surgery	Bangladesh
3	Bertha Tendo Kyozaire	Nutrition	Uganda	4	Nargis Jahan	Speech	Bangladesh
5	Jackie Riley	NGO	UK	6	Zipporah Gathuya	Anesthesia	Kenya
7	Julietta Perondi	Psychology	Argentina	8	Malka Jayathilake	Speech	Sri Lanka
9	Maan Sukte	Myanmar	Speech	10	Manu Prasad	Surgery	India
11	Adeola Olusanya	Surgery	Nigeria	12	Grace Shamba	Social Work	D.R. Congo
13	Beyhan Annan	NGO	Lebanon				



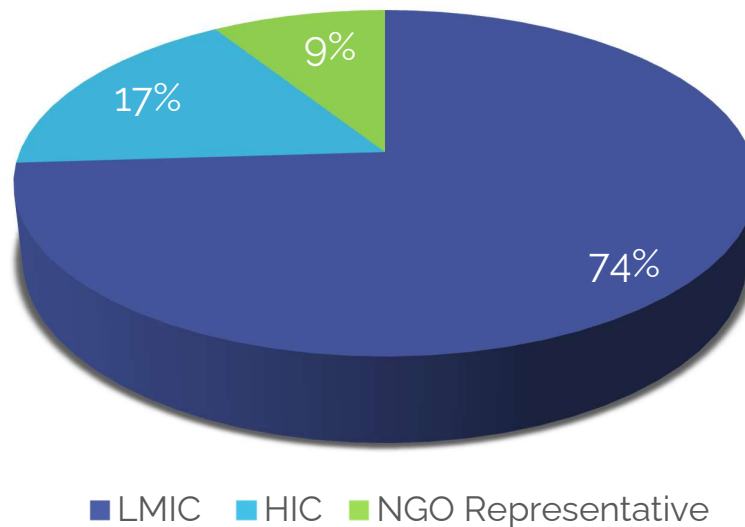
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Glimpses of S4CCC



S4CCC Feedback Survey Summary

Survey Respondent Profile



Participants' Experience of the S4CCC Conference

	N/A	Unhelpful	Somewhat Unhelpful	Helpful	Very Helpful	Total
S4CCC Pre-Conference Process	2%	0%	4%	27%	67%	87
Qiqo Chat/ Zoom Conference Platform	0%	1%	4%	18%	77%	87
S4CCC Plenary Sessions (Opening & Closing)	0%	1%	3%	23%	73%	87
S4CCC Roundtables	1%	2%	2%	25%	70%	87
Overall S4CCC Experience	0%	0%	2%	15%	83%	85

What Participants Appreciated

- The exchange of information and tangible solutions from a range of diverse perspectives
- A well organized, easy-to-navigate technology platform (Qiqo Chat) and conference structure
- A friendly, inclusive environment that felt like an in-person event and a global family
- The opportunity to learn more about Comprehensive Cleft Care and share resources

“

"A whole new idea that was well planned and executed. It kept all the participants eagerly waiting for the conference to happen [and] was very close to a real conference."

"The content was excellent and inclusive. The choice of moderators and panelists was appropriate and the way it was organized made me feel as if I am attending a big conference in person."

"Opportunity to hear how others are managing all over the globe and to learn some inspiring (cost free) ideas from others we can start to implement instantly"

"The content was excellent and inclusive. The choice of moderators and panelists was appropriate and the way it was organized made me feel as if I am attending a big conference in person."

"Top quality learning at your door step."

”

Participant Suggestions on Areas for Improvement

- Identify ways to be more inclusive of the non-English speaking cleft community
- Incorporate slightly longer 'coffee' breaks to enable more participant networking
- Develop a resource bank for participants (Note: CCC resources available through the [CoCP](#))
- Provide more data, detailed methodologies and video examples for solutions suggested
- Hold the S4CCC again and/or increase the frequency of CCC educational programs
- Consider a different conference timing, so those around the globe who were unable to join this time has an opportunity to participate in the next.

“

"I missed some of the presentations as they were happening simultaneously and I felt both were of much importance to my role in cleft care."

"All courses were perfect. I just would like to see more. Maybe, for the future, should be all day long, not only a half day."

"Because it was on one topic (COVID) there was inevitably cross-over between sessions. However, I am not sure how that could be avoided."

"The timing was an issue for me but it's a natural issue that we cannot all be satisfied with"

”

Next Steps Generated by Participants

- Continuing to build on the network and new relationships formed during the conference
- Applying new approaches and techniques learnt to your work
- Sharing key insights and ideas shared at the conference with your CCC team/partners
- Revisiting your CCC team's COVID-19 safety protocols and new operating procedures in light of conference learnings
- Leveraging some of the key learnings as a foundation for a research project

“

“Implement the Standard Operating Procedures / Guidelines for CCC during COVID-19 discussed in this conference for the safety of patients, my staff/team and myself”

“Replicate some techniques discussed that we have not yet attempted in the area”

“Use some of the ideas that were brought up, for a possible research project”

“Empower community health volunteers for outreach work with communities instead of waiting for clients to come to us”

“Keep in touch with people from this network”

”

93%

Participants are highly likely to attend a future S4CCC Conference

S4CCC Team's Response to the Feedback

The S4CCC Team is grateful to all participants, panelists and moderators for experimenting in many new things: a new online platform, a new structure for Roundtables, and new ways of sharing insights across continents and NGOs about how to respond to the pressing challenges of COVID.

It is hard to find timing that is convenient for a live, global event, so we are particularly grateful to those who got up early and stayed up late so that we could learn from your experiences and expertise.

We're very encouraged that so many respondents identified follow-up ideas that emerged through the conference: we hope that this document will be a memory aid and further impetus toward Comprehensive Cleft Care for all, even during this pandemic.

Acknowledgements

S4CCC Advisors, Moderators and Panelists



Thank You!

The S4CCC team was coordinated by Neeti Daftari, Program Manager for Global Initiatives at Transforming Faces, and offers thanks to our skilled conference intern, Tamar Moyal, York University.

We are grateful to the NGO SPONSORS of the Circle of Cleft Professionals

