

2019
-
2025

CoCP ENGAGEMENT PROJECT & STRATEGIC DIRECTIONS

September, 2023





EXECUTIVE SUMMARY

- The Circle of Cleft Professionals (CoCP), founded in 2019, is a global network of **775+ cleft professionals** and charity leaders from **83 countries**. The CoCP is supported by 11 international cleft NGOs¹ and 6 experienced **Comprehensive Cleft Care (CCC)** leaders serve as its programmatic advisors².
- The CoCP's activities include **webinars**, Solutions4CCC **conferences**, the **Journal Reading Club**, **advocacy** initiatives, and the **CoCP Award**. Each initiative is designed to facilitate multidisciplinary learning toward CCC growth in resource-constrained contexts.
- Over **65%** of CoCP event participants are from Low and Middle-Income Country (LMIC) **contexts**, CoCP participant feedback surveys show **90%+ satisfaction**, and CoCP **member engagement** has **quadrupled** since 2019.
- Between April and June 2023, the student-run Oxford Strategy Group (OSG), helped gather insights via a **feedback survey**, two **focus group discussions**, and 6 CoCP Sponsor Leader **interviews**.
- CoCP members and sponsors affirm the **CoCP's effectiveness in meeting its core objectives**.
- Between now and the CLEFT 2025 conference, the CoCP plans to **expand membership**, improve its **communication**, enhance **member benefits**; and continue to **host** a range of virtual CoCP **learning events**.
- **CoCP's overall objectives** should be sharpened: **champion** Low and Middle-Income Country (LMIC)-rooted CCC learning and leadership, **facilitate** 'north-south', 'south-south' and 'inter-NGO' collaboration among multidisciplinary cleft professionals, and **amplify** CCC tools, initiatives and LMIC cleft research.
- The CoCP's audacious and animating goal remains that ***every child and family affected by cleft have access to Comprehensive Cleft Care.***

¹ Akila Bharatha Mahila Seva Samaja (ABMSS), CLEFT UK, Deutsche Cleft Kinderhilfe (DCKH), European Cleft Organization (ECO), Fundación Gantz, Global Smile Foundation, Noordhoff Craniofacial Foundation, Operation Smile, Project Harar, Smile Train, Transforming Faces.

² Dr. Marina Campodonico, Chile; Dr. Mekonen Eshete, Ethiopia; Dr. George Galiwango, Uganda; Dr. Felicity Mehendale, UK; Prof. Roopa Nagarajan, India; Dr. Debbie Sell, UK.

SECTION I

THE COCP (2019-2023): A SNAPSHOT

What is the CoCP?

The CoCP is a global network of cleft professionals and charity leaders committed to promoting **Comprehensive Cleft Care (CCC)** in **resource-constrained contexts**. It is a coalition backed by 11 prominent international cleft NGOs.

CoCP Objectives (2019-2023)

- **Facilitate** collaboration and networking among Cleft Professionals with an interest in multidisciplinary care in resource-constrained contexts.
- **Communicate** the impact and learning occurring within Comprehensive Cleft Care (CCC) projects.
- **Support** local teams' growth in implementing CCC.

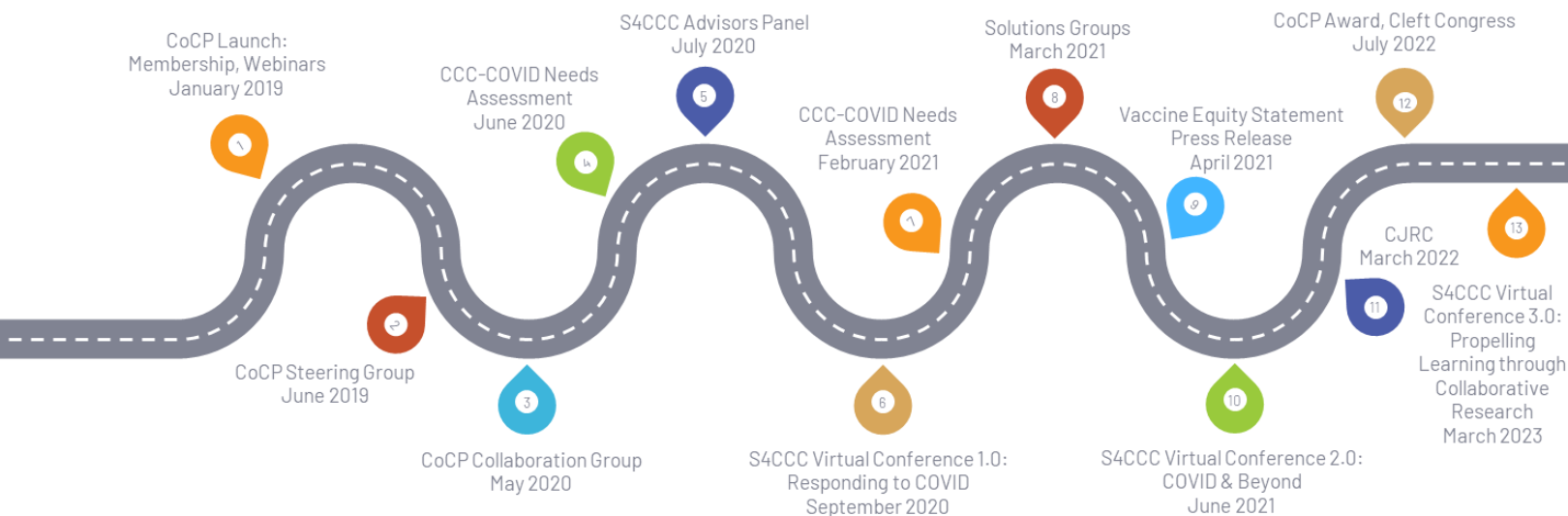
CoCP Genesis

"NGO Day" at the CLEFT 2017 Congress in Chennai generated momentum for cleft professionals with a commitment to LMICs to deepen their networking and learning, beyond the silos of individual cleft NGO movements. Furthermore, cleft care that is led by teams of local, multi-disciplinary professionals was a growing focus for cleft NGOs.

By 2019, rapid improvement in internet bandwidth in many LMIC contexts, along with new remote collaboration tools, made virtual connection points more accessible. These developments only accelerated as the world grappled with the impact of the pandemic in early 2020.

The CoCP's audacious and animating goal remains that *every child and family affected by cleft have access to Comprehensive Cleft Care*.

The CoCP Journey in a Snapshot

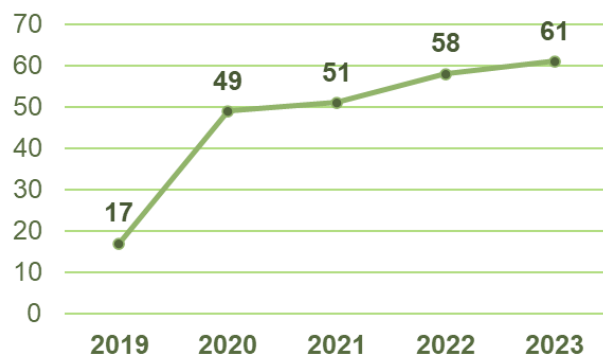


CoCP Events and Initiatives

40 CoCP Webinars

- Average of **1 webinar every 1.5 months**
- Average of **2 panelists per webinar**
- **317** CoCP members have participated in at least one webinar
- **10,000+** YouTube views for CoCP webinars
- **Multidisciplinary Focus:**
- Strong Representation: Psychosocial Care, Speech, Cleft Research, Surgery, Cleft NGO Leadership (5+ webinars each)
- Moderate representation: Dental/ Orthodontics, Team coordination/ management (2-3 webinars each)
- Under-represented: Nutrition, ENT, Nursing: (1 or none)

Avg # Webinar Attendees





About the Webinar Panelists:

- **45%** of webinar panelists hail from LMICs
- **65%** of LMIC panelists are from Asia and Africa
- **Panelist** Organizational Affiliations:
- Smile Train: **33%**
- Transforming Faces: **30%**
- CLEFT UK, ABMSS, DCKH: **5-7%** each
- GSF, NCF, Operation Smile, ECO: **1-4%** each
- None: 14%

3 Virtual Solutions4CCC (S4CCC) Conferences

- **17** Roundtables / Solutions Groups (SGs) across the 3 conferences
- **276** conference participants of which **71%** were from LMIC contexts
 - Primary Discipline representation: Speech Therapists (**28%**), Surgeons (**22%**), Dentists/ Orthodontists (**14%**), Cleft Charity Leaders (**13%**)
 - Moderate Discipline representation (**3%-5%**): Cleft Team Managers/ Coordinators, Nurses, Psychologists, Researchers, Social Workers
 - Low Discipline representation (**0.5% – 3%**): Nutritionists, Anesthetists, ENT
 - Diverse regional representation: Asia (**27%**), Latin America (**23%**), Africa (**23%**), Other (**27%**)
- An average **96%** of participant respondents (n=195) across the 3 conferences found the overall S4CCC experience to be **'helpful' or 'very helpful'**
- An average **93%** of participant respondents (n=195) shared that they were **highly likely to attend a future S4CCC conference**

About the S4CCC Leaders (Roundtable panelists/ SG members):

- **74 S4CCC leaders:** Roundtable panelists/ Solutions Group (SG) members
 - **27** SG members led in 2 or more conferences
 - **69%** of S4CCC leaders are from LMIC contexts
 - Nearly **two-thirds** of S4CCC Leaders are **surgeons or speech therapists**
 - **Nutritionists and nurses** are under-represented in S4CCC leadership
 - Primary S4CCC leader affiliations: Smile Train (**46%**), TF (**41%**)
- **92%** of SG members (n=53) rated their **overall experience** of participating in a Solutions Group as **'excellent'**

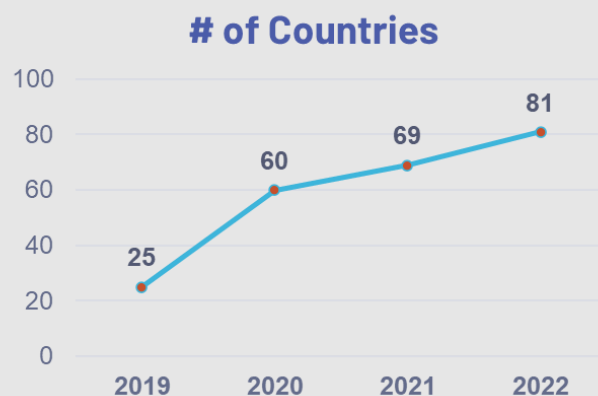
1 CoCP Journal Reading Club (JRC)

- 4 JRC sessions
- 29 participants
- 12 discussion leaders/ presenters of which **67%** were from LMIC contexts
- **90%** (n=29) reported that participation in the JRC increased their motivation, as well as helped develop their skills in engaging with cleft research
- **87%** of JRC participants (n=29) shared that they were likely to participate in a future JRC initiative.

CoCP Award

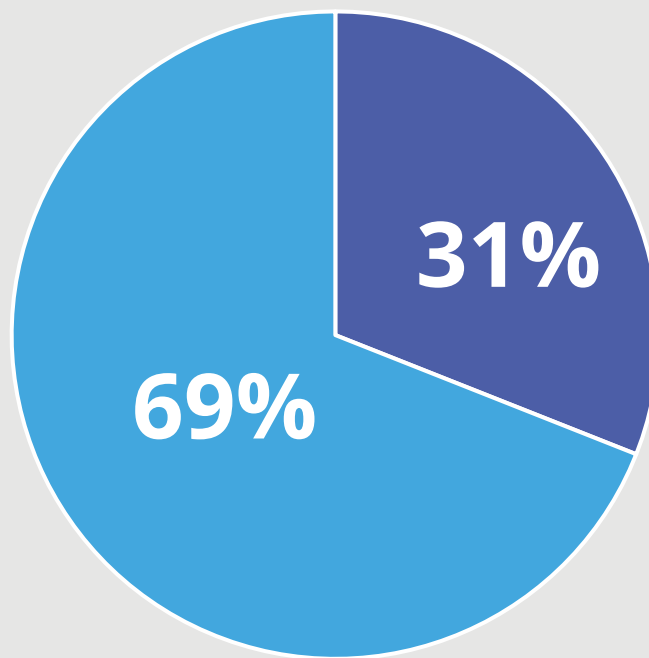
- 14 shortlisted abstracts
- Deliberation by **10** respected multidisciplinary cleft Adjudication Panelists
- Presentation of '*Global cleft care in low-resource settings*' textbook to all 14 award finalists by Dr. Jordan Swanson (Operation Smile)

CoCP Member Profile





** as of August, 2023*

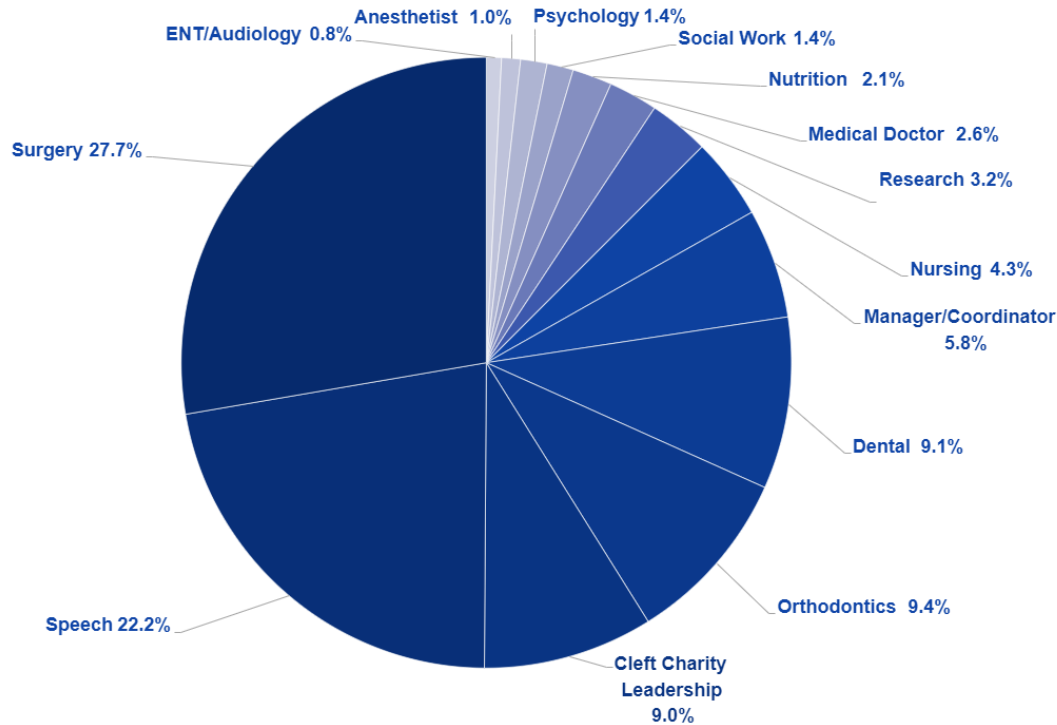


A majority **69%** of CoCP members are from **LMIC** contexts

■ HIC ■ LMIC

CCC Specialty Distribution:

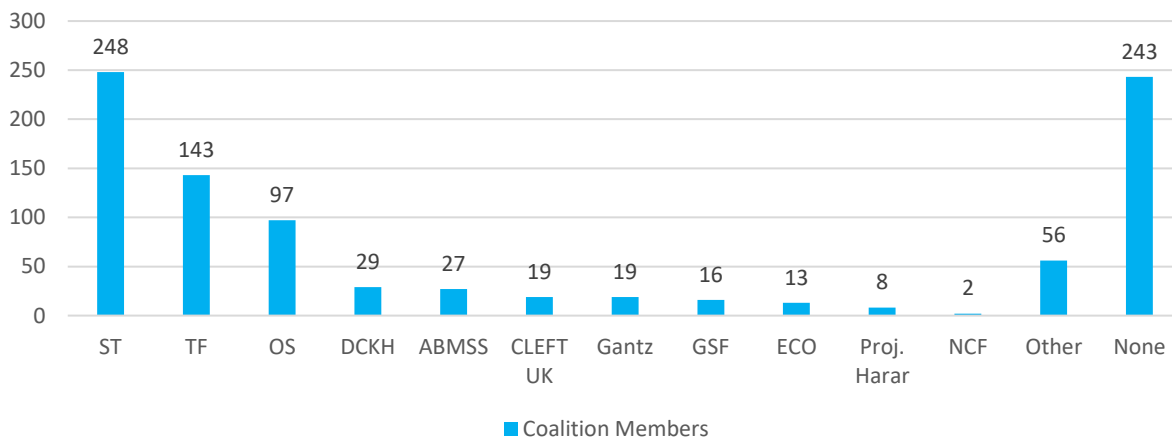
Nearly **50%** of CoCP members are surgeons and speech therapists



- **Sponsor Affiliations:** A third of CoCP members are affiliated with Smile Train; a third are not affiliated with any of the sponsor organizations.

**Several members are affiliated with more than 1 sponsor organization*

CoCP Members: Organizational Affiliation; n = 770



CoCP Member Engagement

- **Member engagement** has quadrupled from 2019 to 2022
- **Over 65%** of event participants overall are from LMIC contexts
- **Over 70%** of S4CCC participants are from LMIC contexts
- **About 50%** of CoCP members have participated in at least 1 online event
- **Over 10%** of members have attended 5 or more CoCP events

Year	Events	Total Unique Attendees	LMIC Representation
2019*	• 8 webinars	60 <i>*estimated</i>	<i>*Data not available</i>
2020	• 13 webinars • S4CCC 1	233	66%
2021	• 8 webinars • S4CCC 2	245	67%
2022	• 7 webinars • CJRC • Cleft Congress: CoCP booth + CoCP Presentations + #TranslateDignity Campaign + Award at Cleft 2022	260 <i>*Inclusive of some Cleft 2022 activities</i>	78%
2023 <i>*As of Aug 15, 2023</i>	• 3 webinars • S4CCC 3	147	67%

SECTION II: THE OSG ENGAGEMENT PROJECT

The OSG Engagement Project

Between April-June 2023, the CoCP solicited the assistance of the [Oxford Strategy Group](#) (OSG), a student-run group affiliated with the University of Oxford, in engaging CoCP members and sponsors. A feedback **survey** was sent to all CoCP members (132 respondents), two **focus group** discussions with CoCP members were facilitated (13 participants), and **interviews** were conducted with CoCP sponsor organization leaders (6 interviews).

Strengths of the CoCP: Member/ Sponsor Perspective

CoCP members and sponsors view the CoCP as:

- Representing a large and **diverse** (both geographically and in terms of cleft speciality) network
- Focusing upon Comprehensive Cleft Care (CCC) in varying **resource-constrained contexts**
- Providing rich opportunities to **share knowledge, resources** and **experiences** beyond participants' regular spheres
- Encouraging the **professional growth** of younger cleft professionals
- Demonstrating **professionalism** and **strong logistical management**
- Offering a unified voice that facilitates **collaboration**
- Bringing together **varied cleft NGOs** toward driving CCC momentum

Top CoCP accomplishments noted include (n=132):

- Hosting interdisciplinary and team-based **CCC discussion** topics (86%)
- Promoting **LMIC-rooted research** (81%)
- Catalysing **HIC/ LMIC collaboration** (80%)

CoCP members **report** (n=132):

- **Increased interest in cleft care** in LMIC contexts (**80%**)
- Expanded **Professional Development** (**79%**)
- Deepened understanding of **NGO strategies** and approaches (**77%**)

“You have to apply before entering the CoCP. It’s self-selecting, people who are in the community are interested in meeting and learning, with new techniques to share on how to improve quality of life of patients.” – FGD Participant

CoCP Network: Insights and Recommendations

Members and Sponsors recommend that the CoCP:

- Provide tools, generate data and sponsor initiatives that will enable local CCC teams to **advocate** with governments and Ministries of Health
- Help build a **global consensus** on the future of cleft care; this includes local and global project collaboration between sponsor NGOs
- Further expand the CoCP network:
 - Invite **more NGOs** into the CoCP coalition
 - **Grow CoCP membership** further
 - Sharpen how the CoCP **communicates** its purpose and goals within LMIC contexts
- Consider how the work required within the S4CCC “Sprint” format impacts the **‘regular work’** of a LMIC cleft professional
- Provide **simultaneous interpretation** in Spanish/ French for online events (82% rated this as either ‘important’ or ‘very important’)
- **Promote in-person** cleft programs/ conferences/ trainings designed for LMIC professionals.

Some respondents requested that the CoCP:

- List recognized **cleft facilities** and **recommend** the best approaches to cleft care in different countries
- Play a more prominent role in spearheading **cleft management education** opportunities (e.g. logistics of NGO / Team Leadership)

“The cleft space is often political and lacks a unified picture of the world. We all have shared issues, but everyone also has their own issues and agenda. The only way we can survive and make a difference is for us to speak in a unified voice.” – CoCP Sponsor, Interview

“I think the CoCP will have a role in getting a consensus where other organizations might struggle. It might be a consensus in priority setting, to do with research areas in global cleft care, and in promoting engagement in global cleft research and clinical endeavors, really putting LMIC at the forefront rather than what has traditionally happened with prioritizing HICs.” – FGD Participant

Program-specific Insights and Recommendations

Webinars

- **71%** of webinar attendees (n=107) rated the overall experience of CoCP webinars as ‘very helpful’ or ‘extremely helpful’
- A majority of members found the webinar topics (**72%**), format (**69%**), facilitation (**68%**), and frequency (**59%**) to be ‘very helpful’ or ‘extremely helpful’
- **48%** of respondents, with a majority from Latin America, report that the webinar timing is not ideal
- Suggestions by members and sponsors include:
 - Organize **multiple sessions** of the same webinar topic to accommodate different time zones
 - Conduct **refresher/re-cap sessions** for the most popular webinars



Solutions4CCC Virtual Conference

- **77%** of S4CCC attendees (n=87) rated the overall experience of S4CCC conferences as 'very helpful' or 'extremely helpful'
- **Over 70%** found the conference topics (**84%**), format (**77%**), and facilitation (**74%**) and to be 'very helpful' or 'extremely helpful'
- A significant number of respondents (**47%** - 'not helpful' – 'somewhat helpful') were dissatisfied with the **length** of the conference. Some shared that 4.5 hours was too lengthy. Staggering conference sessions across a few days was suggested more than once
- Other suggestions by members and sponsors include:
 - Continue emphasis upon **concrete products** rather than simple opinion forums
 - Prioritize **facilitation skills** in Solutions Group leadership selection criteria
 - Consider hosting an **in-person conference**
 - Conflicting feedback for both decreasing as well as increasing the frequency of S4CCC leadership (i.e. Solutions Group) meetings

"There are lots of different ways to do things in Cleft Lip and Palate, and consequently multiple conflicting people can think they know an exclusive best way to do things. Exchanges within the CoCP have always been very respectful, and people don't necessarily come into these forums to share strong beliefs." – CoCP Sponsor

"We also have to realize we come from different, diverse backgrounds and specialties. I wish the CoCP could put some structure and direction to the discussion because sometimes we just keep on talking above/below each other, but never really understanding each other's thoughts because our backgrounds are too different." – FGD Participant (About S4CCC SGs)

CoCP Journal Reading Club (JRC)

- **62%** of CJRC participants (n=32) rated the overall experience of the CJRC as 'very helpful' or 'extremely helpful'
- A significant number of respondents found the CJRC format (**62%**), facilitation (**62%**), topics (**62%**), and timing (**50%**) to be 'very helpful' or 'extremely helpful'
- Suggestions by members and sponsors include:
 - Offer members ongoing **access to specific journals**
 - Enable participants to engage with research within their respective **disciplines** (vs. an interdisciplinary approach)
 - **Translate journal articles** for discussion into Spanish and French

CoCP Communications

- Overall, members are happy with CoCP Platforms and Communications
 - **Over 70%** (n=132) describe the CoCP website, the S4CCC website, and current CoCP communication via emails and calendar invites to be helpful/very helpful
 - **21%** of respondents suggest that CoCP's performance on social media is an area that needs improvement
- A few members expressed challenges in locating calendar invitations or webinar links
- Suggestions by members and sponsors include:
 - Incorporate more visual content such as images and **short videos** in CoCP's social media channels
 - Members prefer **email** over Slack. Several members and sponsors suggest transitioning to **WhatsApp**
 - A few members request easier access to webinar and conference **recordings**

SECTION III:

STRATEGIC DIRECTION (2023-2025) - THE WAY FORWARD

Key Take-aways from Sections I and II

- Members and Sponsors assert: ***The CoCP has been effective in meeting its core objectives.***
- The CoCP has seen both its membership network expand and member engagement steadily deepen. Half the membership has actively participated in live online events, and the remaining 50% rely upon post-event video recordings. There is potential to **engage a larger proportion of CoCP members in live online events**, which we feel have a greater potential for stimulating concrete action toward CCC.
- The CoCP has consistently maintained a **multidisciplinary, LMIC, and inter-NGO focus**, which is evident in the membership, leadership and participant profiles for CoCP initiatives. Nutrition, psychology, social work, and ENT are not as well-represented, presenting an **opportunity for growth** in these areas.
- The **CoCP's strategic priorities** over the next two years include:
 - Developing an CoCP "affiliate organization" strategy (e.g. Cleft Research Organizations)
 - Improving membership communication and enhancing member benefits
 - Hosting regular webinars, journal reading sessions and a virtual conference
 - Facilitating regional virtual gatherings to promote south-south networking and collaboration.
 - Ensuring an impactful presence at the 2025 Cleft Congress

CoCP Objectives: Renewed

Based on member feedback, the following are the CoCP's draft **revised objectives**:

1. **Champion** Low and Middle-Income Country (LMIC)-rooted Comprehensive Cleft Care (CCC) learning and leadership
2. **Facilitate** 'north-south', 'south-south' and 'inter-NGO' collaboration among multidisciplinary cleft professionals
3. **Amplify** CCC tools, practical initiatives and LMIC cleft research

CoCP Network Expansion, Member Engagement and Events Plan (2023-2025)

Strategic Priority		Event/ Activity	Objectives Addressed	Timeline
1	Expand CoCP coalition to include regional or international groups that promote knowledge dissemination and offer opportunities for CoCP members to actively engage with research and advocacy initiatives	Design a CoCP “affiliates strategy” with cleft organizations focusing upon priorities such as LMIC cleft research <i>*The CoCP offers access to a diverse group of cleft professionals; alongside opportunities for visibility on the website, social media channels, and prominent international forums like the Cleft Congress</i>	1, 2 & 3	Mid-2024
2	Enhance the benefits associated with CoCP membership	Negotiate improved access to journal articles focusing on multidisciplinary cleft care within LMIC settings Provide certificates for leadership/ participation in CoCP initiatives such as the S4CCC, CJRC, etc.	3	Mid-2024
3	Improve Communication on the CoCP and its initiatives	Upgrade the CoCP Website: - Amplify access to CCC tools and resources by sponsor NGOs and others and promote the professional development opportunities available - Improve upon the organization of resources by creating a centralized, filtered user-friendly hub - Enhance accessibility in Spanish and French - Incorporate more visual/ interactive content such as short videos in CoCP’s social media channels	2 & 3	Q3 2024

4	Identify a new networking platform for members	<p>Discontinue the use of Slack for CoCP and explore the possibility of establishing a LinkedIn group for networking purposes.</p> <p><i>*WhatsApp has been recommended as a promising platform for networking in LMIC contexts. However, the significant moderation required and security implications make it impractical for this purpose.</i></p>	2 & 3	Q4 2023
5	Introduce a CoCP initiative to promote south-south collaboration amongst cleft professionals	<p>Pilot hosting regional virtual gatherings</p> <ul style="list-style-type: none"> - Asia, Africa, Latin America - Focus upon broad cross-disciplinary CCC topics. - Emphasize intra-regional networking and knowledge-sharing 	1, 2 & 3	2024
6	Host regular CoCP webinars in the existing format	<p>Boost the CoCP webinar experience and accessibility:</p> <ul style="list-style-type: none"> - Improve promotion and access to recordings - Promote innovative ways for members to interact with the webinar recordings e.g., certificates & reflection prompts for CCC teams <p><i>*Alternate webinar timings and/or multiple sessions for popular webinar topics were recommended by some respondents, especially in Latin America. Unfortunately, later timings will exclude Africa and Asia. Hosting multiple sessions of the same webinar is not logistically feasible for the CoCP support team at this time.</i></p>	1, 2 & 3	2024, 2025
7	Facilitate CJRC sessions in a more viable format	<p>Incorporate single-session journal reading discussions</p> <ul style="list-style-type: none"> - 3-4 multidisciplinary JRC sessions in 2024 interspersed within the CoCP webinar schedule - Includes mandatory pre-reading of journal articles and breakout groups for guided discussion - Participants will no longer be required to commit to attending <u>all</u> CJRC sessions 	1, 2 & 3	2024 (+ potentially in 2025 if it proves successful)

8	Host the S4CCC 4.0 conference as a precursor to Cleft Congress 2025	S4CCC 4.0 subject matter will center upon prominent Cleft 2025 topics : <ul style="list-style-type: none"> - Invite groups interested in presenting at Cleft 2025 to engage in the Solutions Group sprint process. - Offer Spanish + French simultaneous interpretation 	1 & 2	Q1 2025
9	Plan for CoCP presence at Cleft Congress 2025 that highlights CCC in the Global South	CoCP activities at Cleft 2025 will include : <ul style="list-style-type: none"> - CoCP Award: Shortlist LMIC papers - Paper Presentations: Support for shortlisted award candidates - CoCP In-person Event: Facilitated member networking session/ short panel discussion 	1,2 & 3	Q3, Q4 2025

**The Authors of this report acknowledge with gratitude the visionary leadership of cleft NGO leaders who have made the CoCP possible:
Dr. Ruben Ayala, Hugh Brewster, Neeti Daftari, Gareth Davies, Dr. Gaurav Deshpande, Dr. Monica Dominguez, Alexander Gross, Dr. Usama Hamdan, Linus Lee, Ximena Ovalle, Dr. Dushyant Prasad, Jackie Riley, Pamela Sheeran, Mr. Brian Sommerlad, Andrea Weiberg*