



SOLUTIONS4CCC REPORT

Propelling Learning Through Collaborative Research



2023

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Overview

For this **third** iteration of the Solutions for Comprehensive Cleft Care (S4CCC) conference, **37** cleft professionals drawn from **7** disciplines and hailing from **23 countries** stepped forward as Solutions Group (SG) members. Inspired by the momentum generated at the CLEFT 2022 conference in Edinburgh (UK), their task was to develop and test **practical recommendations** for moving Comprehensive Cleft Care forward in Low and Middle-Income Countries (LMIC) on the following topics:

- Getting Started with Patient-Reported Outcomes (SG1)
- Initiating and Sustaining Patient and Parent Support Groups (SG2)
- Integrating Psychosocial Care Across Cleft Specialties (SG3)

From January to March 2023, Solutions Groups (SGs) members participated in a ‘sprint’ of 5 fortnightly 75-minute virtual meetings to research, develop and test hypotheses, and prepare to facilitate a global Roundtable discussion at the *S4CCC: Propelling Learning Through Collaborative Research* virtual conference on March 23, 2023.

Over **130 participants**, largely drawn from LMIC regions, contributed to the dialogue which can be viewed in its entirety on the Circle of Cleft Professionals (CoCP) [YouTube Channel](#).

Introduction

Can you hear it? It is the sound of progress. Cleft care is rapidly evolving, fueled by passionate LMIC professionals and supported by HIC allies and collaborators.

The **11 leading NGOs** who sponsor the Circle of Cleft Professionals (CoCP) deserve praise for enabling members of multiple NGO movements to work together harmoniously in this innovative forum. Better care for patients and families affected by cleft is surely the result.

While only a few Solutions Group (SG) members would have previously considered themselves experts on the topics explored at this year's S4CCC, all are experienced cleft professionals with a deep commitment to advancing CCC in LMIC contexts. They merit thanks for taking on this challenging initiative, with special recognition to our 6 SG Co-chairs.

We are inspired by the substantial response to each SG's research survey. We feel propelled forward by each SG's guideline recommendations. We are *amazed* by the energy and enthusiasm of participants in the Roundtables. All should take pride in the very positive participant assessment of the conference!

We hope that each SG's Guideline Recommendations will spur further development of LMIC-focused tools, research, dialogue, and momentum.

Hugh Brewster & Neeti Daftari, S4CCC Hosts

on behalf of the Circle of Cleft Professionals.



HUGH BREWSTER



NEETI DAFTARI

Summary of Sprint Process



Connecting – Solutions Group (SG) members, Co-Chairs and support team became acquainted, established shared expectations for participation, and began reviewing key topical resources.



Exploring – SGs discussed their learning, brainstormed key questions, and identified experts to consult.



Surveying – SGs consolidated topical knowledge, prioritized survey questions, and compiled a list of individuals to invite to complete a survey.



Analyzing – SGs compared notes from their interviews and survey analysis and began to form guideline recommendations.



Recommending – SGs finalized their recommendations and rationale and planned their Roundtable presentation.



Facilitating – SGs hosted a 75-minute Roundtable discussion at the 2023 S4CCC Conference.

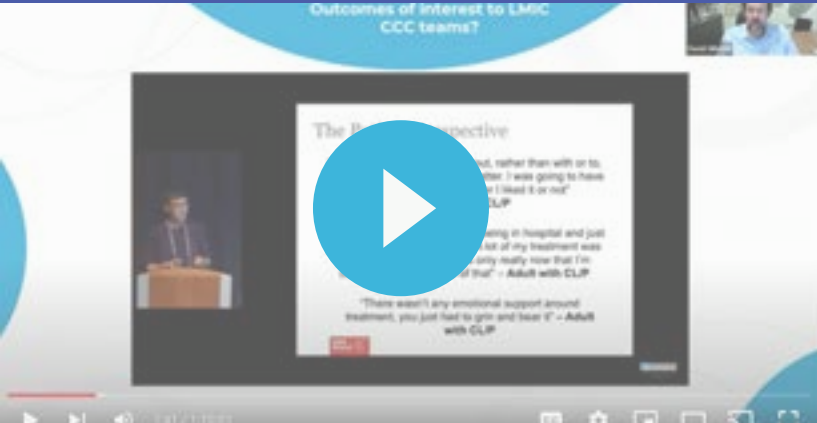


Consolidating - SGs debriefed their Roundtable, considered participant feedback, and planned to capture their final topical Guideline Recommendations in written form.

01

Opening Plenary

[Watch the Recording](#) >



02

SG1

Getting Started with Patient Reported Outcomes (PROs)

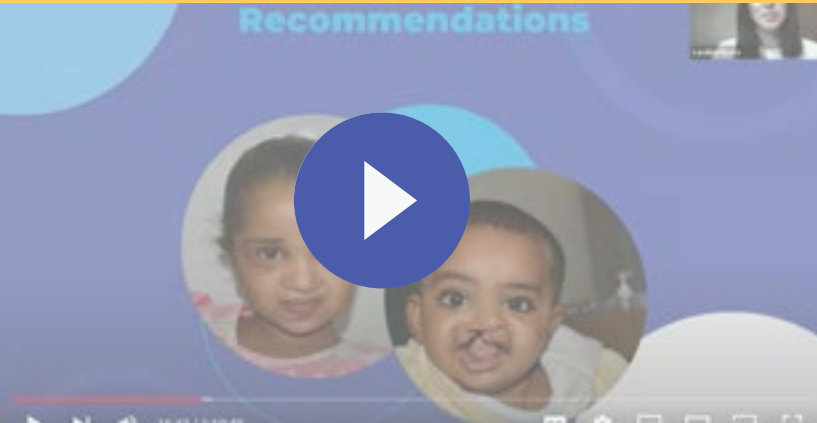
[Watch the Recording](#)

03

SG2

Initiating and Sustaining Parent and Patient Support Groups

[Watch the Recording](#) >



04

SG3

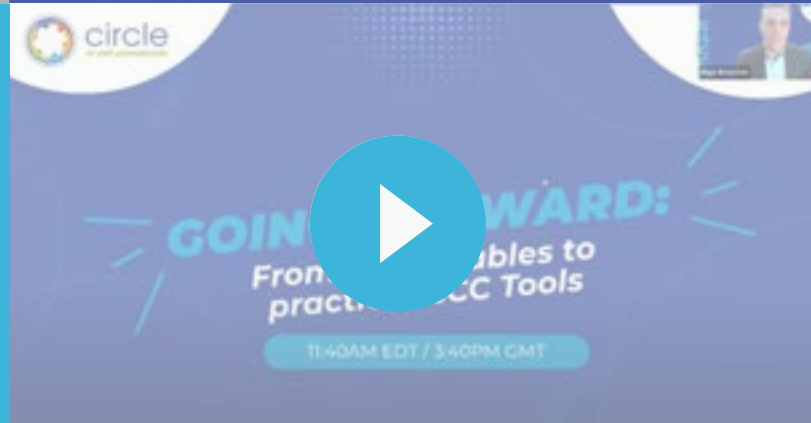
Integrating Psychosocial Care Across Cleft Specialities

[Watch the Recording](#)

05

Closing Plenary

[Watch the Recording](#) >



SG Members

The substantial investment of time and expertise, not to mention a spirit of collaboration, from the following global cleft professionals made both the S4CCC Roundtable and the Guideline Recommendations possible:



DR. PUNEET BATRA



DR. DAVID GILLETT



DR. MELISSA ANTONELI



DR. YOURI ANASTASSOV



DR. CAROLINA CRAMARO



DR. MONICA DOMINGUEZ



DR. MEKONEN ESHETE



DR. CARLA FLORIN



DR. MICHAEL GOLDWASSER



SCARLETTE NORAMBUENA



DR. ADEOLA OLUSANYA



DR. DEBBIE SELL



MAAN SUKTE



DR. DIANA BOHORQUEZ



GARETH DAVIES



ZAINAL AHMAD



DR. MARINA CAMPODONICO



JAVIERA CORNEJO



HELENA CULLIS



DR. DAISY MASIS



LINUS LEE



DR. FELICITY MEHENDALE



KIM ROBERTSON SMITH



FRANCISCA SALAZAR



DR. B. SUBRAMANIYAN



**PROF. LOLA
ORENUGA**



**DR. SENEM
ZEYTIINOGLU SAYDAM**



**MARIANA
ALFACE**



**DR. SHIBANI
DAS**



**MATIAS
GONZALEZ**



**MALKA
JAYATHILAKE**



**PROF. ROOPA
NAGARAJAN**



JULIETA PERONDI



CAROLINA RIVERA



SWETHA SRIDHAR



**PHANOMWAN
YOODEE**

SG



YALEXIS BARR



HUGH BREWSTER



NEETI DAFTARI



ANDREW INGLIS

Support Team



DANAKA ROBERTSON



TAYLOR SNODGRASS



KRISTIAN WYKES



DR. MARINA CAMPODONICO



DR. MEKONEN ESHETE



DR. GEORGE GALIWANGO

S4CCC Advisors



DR. FELICITY MEHENDALE



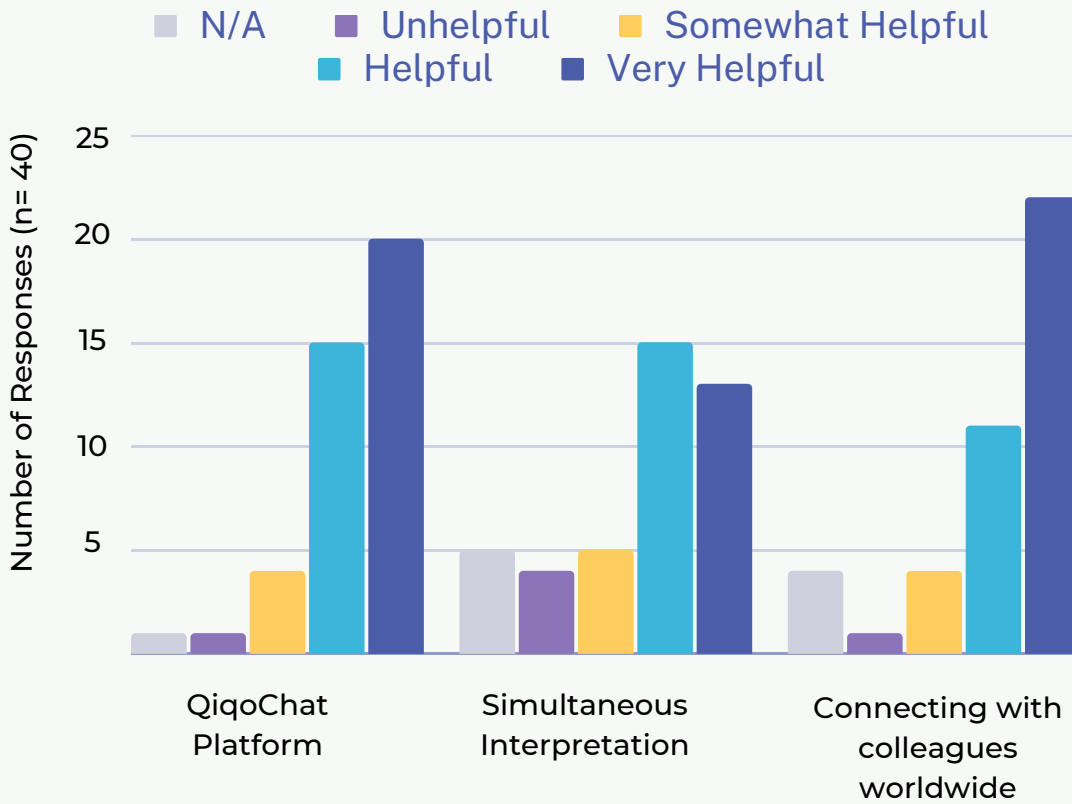
PROF. ROOPA NAGARAJAN



DR. DEBBIE SELL

Summary of S4CCC Participant Feedback

Feedback



91%
Highly likely to attend a future S4CCC Conference

92%
found their overall S4CCC experience to be helpful

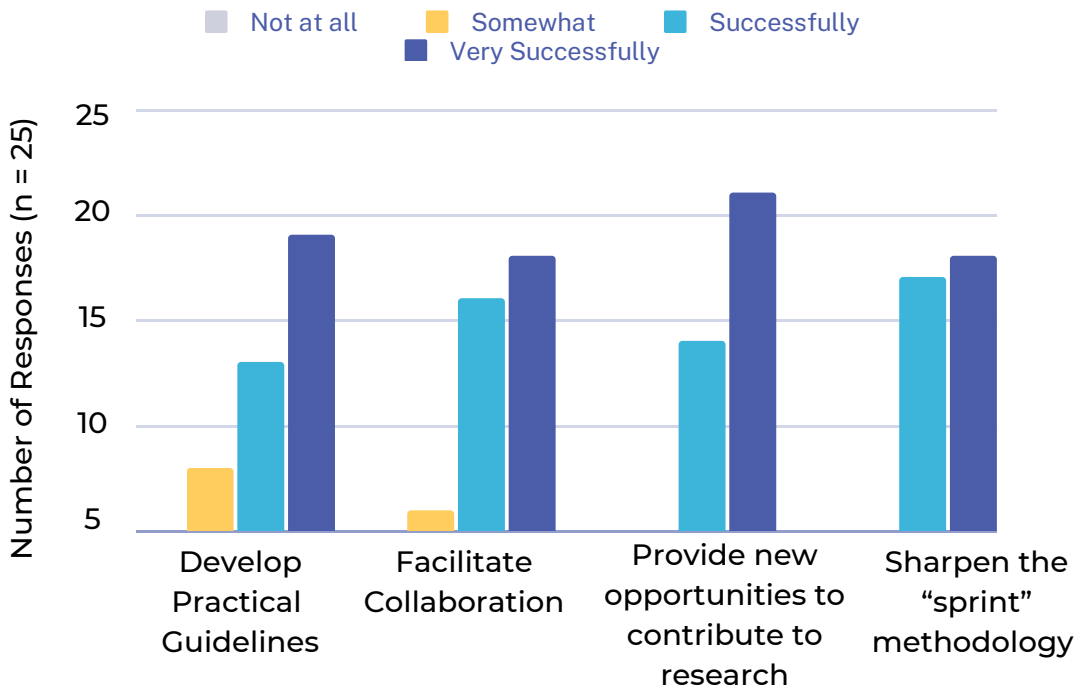
“Each session was well presented, participant engagement and participation were evident through all 3 sessions, and the immediacy of the platform influenced interactions so that participants and presenters were actively engaging with each other.”

“Representation from all disciplines (e.g. nursing) would assist to identify barriers/strategies to overcome and initiatives not currently explored.”

“S4CCC provided numerous solutions to comprehensive cleft care and helped me to understand how this can be achieved around the globe.”

“The Spanish interpretation experienced a few interruptions which occasionally made it hard to follow.”

Summary of SG Member Feedback



96%
highly likely to participate in an SG in the future

92%
rated their experience as excellent

“
It is a rare platform to see the point of views of other cleft professionals not limited by LMIC/HIC contexts nor specialty barriers. S4CCC showcases our common goals. This is quite uplifting.
”

“
I would have liked the opportunity for a moment of sharing and discussion with the other members of the other Solutions Groups
”

“
I really appreciated the opportunity to learn more about these interesting topics that change the way that we see multidisciplinary management on cleft patients
”

“
A short reading or abstract ahead of time with presenters information may be especially useful for those who were not part of the SG groups
”

To learn more about the sprint process please contact info@cleftcircle.org

Roundtable Participants

Ms. Adelaide Emma Gyamera
Dr. Adeola Olusanya
Sra Adriana Quiroga
Dr. Afieharo Michael
Sra Alejandro Tagle
Ms. Alice Hsieh
Ms. Ana Paris Leal
Ms. Angelica Campos
Dr. Bijoy Das
Bonn Miguel Daguman
Dr. Bruna Costa
Camila Osorio
Ms. Christina Mellies
Corina Gill
Courtney Mollenhauer
Mr. Đạt Lê
Ms. Deepalakshmi Sriram
Ms. Dianne Erquiaga
Lic. Diego Sánchez
Dr. George W. Galiwango
Dr. Matt Fell
Dr. Michael Nebeker
Dr. Elizabeth Igaga
Erika Bostock
Mr. Fernando Liigot
Sra. Gabriela Reinoso
Dr. Gonzalo Reynaldo Torrez Cruz
Ms. Grace Peters
Ms. Haingonirina Valerie Rakotonarivo
Dr. Hannah Bergman
Hari Kishore
Ms. Hayley Benbow
Dr. Hedieh Hashemi H
Dr. Ihsan Mohammed
Sra. Isabel Maria Aldana Palacios
Dr. Ivan Ginev
Ms. Jackie Riley
Mrs. Jana Anguelova
Ms. Janella Christie
Ms. Juliet Eyram Senoo
Magister Julieta Villca Guzman
Ms. Kübra Kızılırmak
Dra. Lidia Tamayo Espinosa
Ms. Lismore Nebeker
Mr. Khalid Malikk
Maria del Rocio Lu Chang Say
Ms. Maria Iana Carmen E. Samson
Sra. Mariana Mansilla
Mariyana Ivanova
Mayank Khandelwal
Dr. Mohammed Junaid
Dr. Monica Dev
Mukunda Reddy
Dr. Nancy Edith Rojas Holguin
Mme. Narindra Léonie Raheisoa
Dr. Navleen Kaur Bhatia
Dr. Nicola Stock
Nirina Laurence
Dr. Nirina Mandrano
Ms. Nonhlanhla Khoza
Nora Anthuane Ruiz Valverde
Prof Oluranti daCosta
Dr. Praveen Ganesh Natarajan
Dr. Rajib Khadka
Mme. Rinasoa Vololontsahondra
Dr. Rinkle Sardana
Lic. Rosaura Rodriguez Soliz
Sagar Jangam
Mr. Sanjaykhanna V K
Ms. Saskia Foulds-Holt
Dr. Savitha Hariharan
Mme. Sehenon Ravonimalala
Shruti Bijapur
Dra. Silvia Torres Cavallo
Mr. Sriram M
Ms. Stefanie Huter
Tim Bressmann
Dr. Timothy Ogunlade
Dr. Triona Sweeney
Dr. Usama Hamdan
Ms. Vanessa Enriquez
Dr. Varun Menon P
Ms. Wen Tzeng
Ms. Ximena
Ms. Yi Hsuan Lin
Ms. Yi-Ling Chen
Dr. Yolanda Ricela Flores Santivañez
Zuraini Ghazali



Contact

Solutions 4 Comprehensive Cleft Care

www.solutions4ccc.com

Circle of Cleft Professionals

www.cleftcircle.org

info@cleftcircle.org

Our NGO Sponsors



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