



SOLUTIONS GROUP 4

# SUPPORTING PARENTS IN SHARED DECISION-MAKING

S4CCC Guideline Series 2025 //

Inclusive Approaches, Lasting Change



# CONTEXT

## What is “Shared Decision-Making”?

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

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

Shared decision-making optimizes healthcare by:

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

## How were these recommendations developed?

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

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

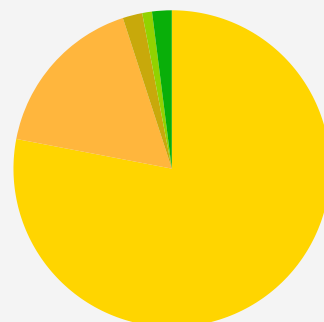
 Speech Professional, UK

**95%**

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

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

● Strongly Agree	<b>78%</b>
● Agree	<b>17%</b>
● Neutral	<b>2%</b>
● Disagree	<b>1%</b>
● Strongly Disagree	<b>2%</b>



# #1

## RECOMMENDATION #1

# Invite family members to participate fully in treatment decision-making

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

## Rationale

- Parents and caregivers may not be aware of their potential role in treatment decision-making.
- Cultural norms are a barrier to SDM in many regions.

**“Patients may defer to healthcare providers and not actively participate in decisions.”**

/ Speech Professional, Ethiopia

**31%**

of survey respondents indicated ‘Cultural norms’ as a barrier to implementing SDM

**“Traditionally, there is a cultural tendency to strongly respect the opinions of physicians, and patients and their families are inclined to follow the doctor’s recommendations.”**

/ Speech Professional, Japan

- Literacy and language/dialect differences may also impact the ability to facilitate SDM.
- There are a lack of decision-making aids/tools in CCC.

**46%**

of survey respondents indicated ‘Patient/family literacy’ as a barrier to implementing SDM

**72%**

of respondents indicated that ‘visual aids for patients and families’ would be helpful for facilitating SDM



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

— Speech Professional, Nigeria



# #2

## RECOMMENDATION #2

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

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

#### Rationale

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

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

/ Psychologist, England

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

/ Psychologist, Wales

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

25%

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

79%

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



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

— Speech Professional, India





# #3

## RECOMMENDATION #3

### Sensitize healthcare providers to the benefits of shared decision-making

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

#### Rationale

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

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

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

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

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

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

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



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

— Surgeon, Spain



# #4

## RECOMMENDATION #4

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

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

### Rationale

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

27%

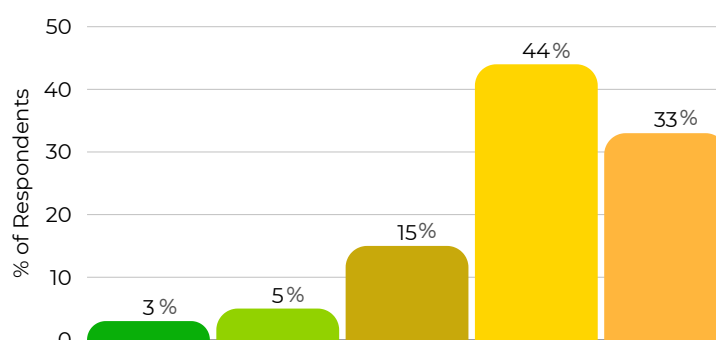
of respondents indicated 'healthcare provider knowledge of SDM principles' as a barrier to implementing SDM

Only 33%

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

### My team successfully demonstrates shared decision-making practices

- Strongly Agree
- Agree
- Neutral
- Disagree
- Strongly Disagree



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

— Psychologist, Bulgaria

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# #5

## RECOMMENDATION #5

### Ensure patient and parent perspectives are included in future work

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

#### Rationale

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

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

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

— Surgeon, Madagascar



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## CONCLUDING THOUGHTS:

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

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## RESOURCES:

### Click to access the following

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

