



## Solutions Group 1

**S4CCC Guideline Series:**

# GETTING STARTED WITH PATIENT REPORTED OUTCOMES (PROS)

Propelling Learning Through Collaborative Research  
May 2023



# CONTEXT

## What do we mean by “Patient Reported Outcomes” (PROs)?

PROs are reports that come directly from patients about how they function or feel in relation to a health condition and its therapy, without interpretation by a physician or anyone else[1].

## Why are Patient Reported Outcomes of interest to LMIC CCC teams?

- PROs enhance patient engagement and improve treatment adherence and outcomes for the individual patient.
- PROs enable CCC teams to monitor care and evaluate protocol changes.
- PROs facilitate comparisons of outcomes across teams, protocols, and populations.
- PROs gather data for auditing and research purposes.
- PROs can be incorporated into CCC protocols in LMICs without great expense

## How did we develop these recommendations?

A diverse group of 13 cleft professionals participated in a 3-month research ‘sprint’ that included a global survey that was completed by 130 cleft professionals from 39 countries. The recommendations which follow were presented and discussed at the March 2023 S4CCC Conference.

[1] Valderas JM, Kotzeva A, Espallargues M, et al. Qual Life Res 2008: 179-193

# RECOMMENDATION

## #1



### Listen

Start by encouraging every CCC professional on your team to ask open questions [2] of patients and families about their treatment to date. Provide a venue for CCC professionals to share what they are hearing from patients/families and discuss together what it might mean.

*Note: Think carefully about who should ask the patient/parent these open questions. If possible, it should not be the treating clinician.*

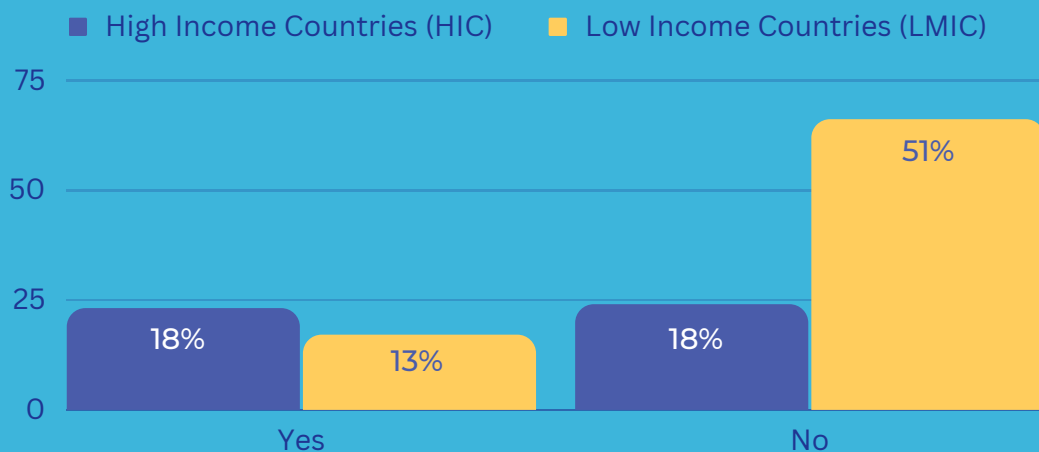


### Rationale

Research has shown that person-centered care [3] results in improved outcomes and patient-reported outcomes (PROs) can increase patient involvement in their care and improve shared decision-making.

[2] An open question cannot be answered with a simple "yes" or "no" response. Open questions are used to encourage discussion, exploration, and the sharing of opinions.

[3] Patient-centered care places the individual at the center of their care. It emphasizes the importance of understanding and addressing the unique needs, preferences, values, and goals of each patient.



**Use of PROs by CCC Professionals: HIC vs. LMIC (n=130)**

# RECOMMENDATION #2



## Learn

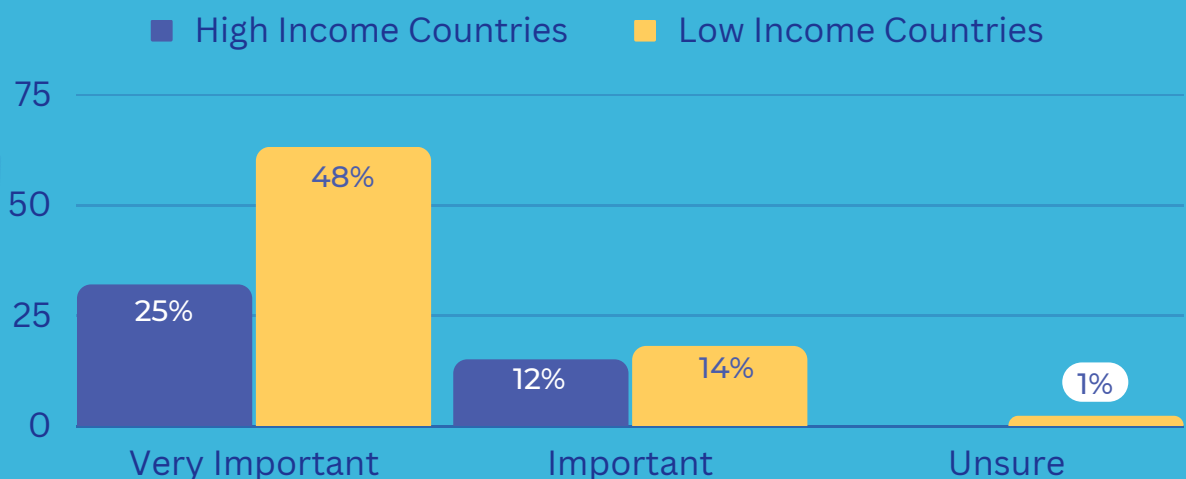
Host opportunities for all CCC professionals on your team to learn about PROs as a means of improving patient outcomes and minimizing the burden of care. Review and discuss common PRO scales in use globally and how they could be applied in your team.

*Note: Most respondents who currently use PROs use them for clinical purposes with individual patients. Cohort-based research and analysis will be a promising next step.*



## Rationale

- 99% (n=130) of Cleft Professionals say PROs are an 'important' or 'very important' tool for cleft care management
- About 50% LMIC respondents are not familiar with any published PRO scales



**Importance of PROs in the Management of Patients with Cleft: HIC vs. LMIC**

# RECOMMENDATION #3



## Select

Choose a validated PRO scale and nominate a “PRO champion” on your team. Plan small, simple and contextually relevant steps toward implementing a PRO with your patients/families, initially as a means of informing clinical approaches.

*Note 1: The two most widely validated scales in multiple languages are CLEFT-Q and the Intelligibility in Context Scale (ICS)*

*Note 2: There is limited evidence of active use of PROs in LMIC cleft teams. A small number of PROs currently have non-Western language validated translations..*



## Rationale

- Our survey found that Speech, Psychosocial and Appearance were the most important areas in which to use PROs.
- Since PRO use is not yet common, nominating a “PRO champion” to raise awareness among cleft team members and take ownership of the introduction is an important first step.

*Note: The literature is clear that cleft teams must use a validated scale without shortening it. Patients, however, do not need to complete all of the available CLEFT-Q scales in any given study or clinical encounter. Each scale is designed to function independently.*

“PROs are reports that come directly from patients about how they function or feel in relation to a health condition and its therapy, without interpretation by a physician or anyone else.”



# RECOMMENDATION #4



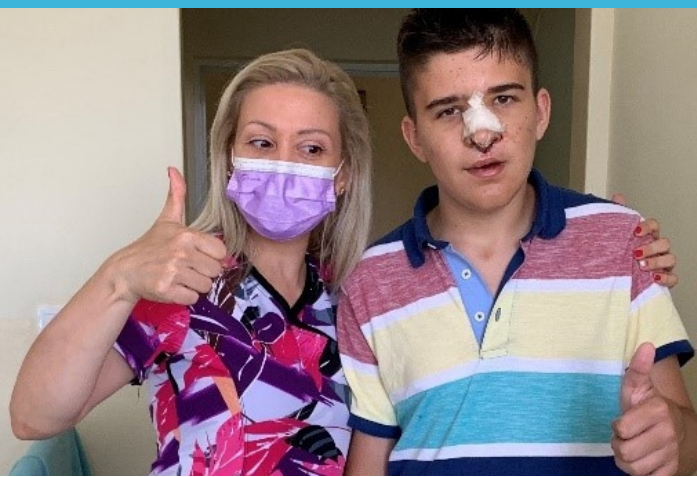
## Support

Ensure that adequate time and resources are allocated to gather data and that psychosocial support is available for patients/families as they complete the PRO assessments.



## Rationale

- Parents and Patients may find responding to PRO questions distressing, particularly if they are dissatisfied with their clinical results.
- PROs require additional time for patients/parents to complete, and additional staff time to administer and document results.
- Cleft Teams need time to select appropriate PRO scales, develop systems to review and discuss results, and to consider protocol changes as a result of PRO findings.



# RECOMMENDATION #5



## Experiment

Establish milestones for patient assessment and plan for the whole CCC team to review implementation successes and challenges. Discuss emerging data, and consider implications for your team-based care, on a regular basis.



## Rationale

- Start small and focus on achievable objectives, rather than trying to implement a large-scale program all at once. This can help to ensure that the program is feasible and sustainable, and can help to build momentum and support for further improvements over time.
- Implementing PROs should be an iterative process, with ongoing opportunities for learning and improvement.
- By taking a patient-centered approach and involving patients and their families in the process, it is possible to achieve meaningful improvements in patient outcomes and experiences.





# NEXT STEPS

Focus groups can be a very helpful tool when launching use of PROs – developing the capacity to facilitate these discussions within your team will pay dividends. To ensure honest feedback from patients and families, consider nominating a non-treating clinician for this role. Remember that nurses, psychologists, social workers (and other members of the multidisciplinary team), or patient support groups can provide emotional support and a non-judgmental environment for patients to express themselves. Long-term follow-up with PROs can provide valuable insights post patient discharge. Overall, adequate funding is necessary for PRO implementation, education, and PRO selection.

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## Additional Resources

- [Solutions Group 1 Roundtable Video Recording](#) on the CoCP YouTube channel
- [ICHOM: Patient-Centered Outcome Measures](#)
- Other Patient/ Caregiver-Reported Outcome Scales:
  - [Focus on the Outcomes of Communication Under Six \(FOCUS\)](#)
  - [The Speech Participation and Activity Assessment of Children \(SPAA-C\)](#)
  - [VELO: A Velopharyngeal Insufficiency Quality of Life Measure](#)
- [Summary Analysis of CLEFT-Q-related Articles - 1](#)
- [Summary Analysis of CLEFT-Q-related Articles - 2](#)

