



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.

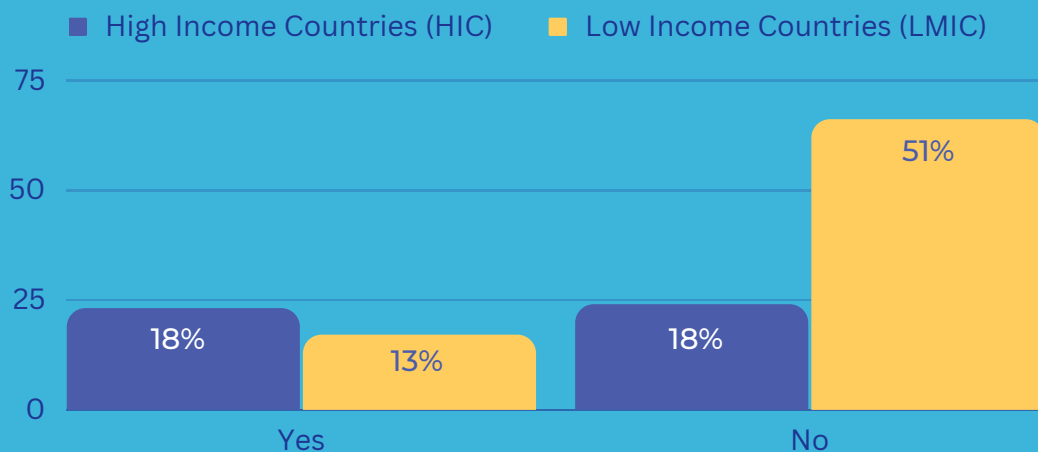


Rationale

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

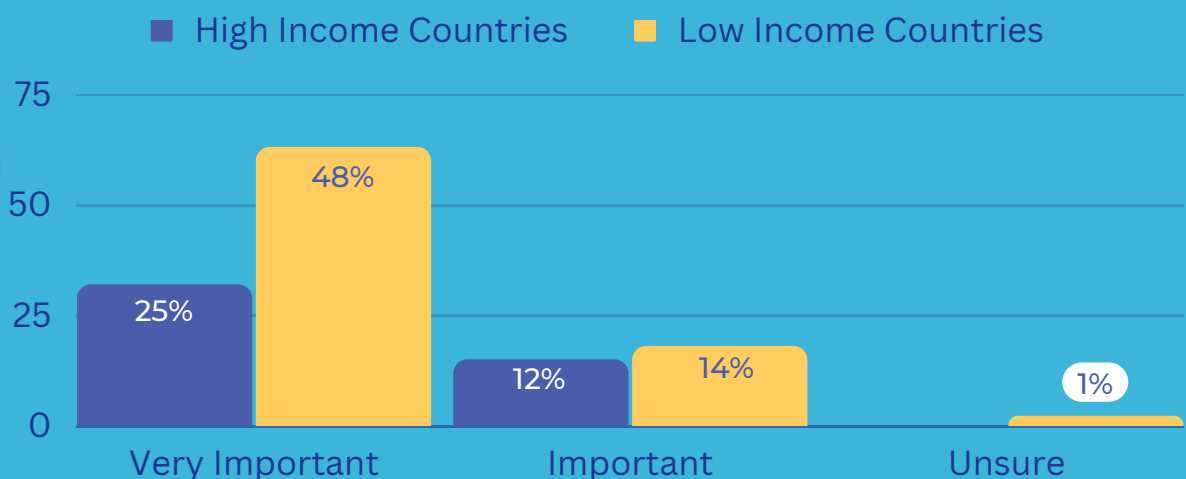
Host opportunities for all CCC professionals on your team to learn about PROs as a means of improving patient outcomes and minimizing the burden of care. Review and discuss common PRO scales in use globally and how they could be applied in your team.

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](#)





Solutions Group 2

S4CCC Guideline Series:

INITIATING AND SUSTAINING PARENT & PATIENT SUPPORT GROUPS (PSGS)

Propelling Learning Through Collaborative Research
May 2023



CONTEXT

What do we mean by “Parent and Patient Support Group”?

Parents and individuals empathetically support one another via an organizational structure that also provides support to a local cleft team.

Why are Parent and Patient Support Groups (PSGs) of interest to LMIC CCC teams?

PSGs are an extra resource that supports parents and patients in a structured, unique way. PSGs can also support cleft advocacy efforts and raise community awareness, drawing from the lived experiences of their members. They can also effectively lobby for better resourcing of cleft care.

How did we develop these recommendations?

A diverse group of 12 cleft professionals participated in a 3-month research ‘sprint’ that included a global survey that was completed by 190 cleft professionals. A second survey was circulated and received 182 responses from individuals in 39 countries who have accessed cleft care. Analysis of the surveys shaped the recommendations which were presented and discussed at the March 2023 S4CCC Conference.

RECOMMENDATION

#1



Recommendation

Enhance awareness amongst cleft teams about the unique importance of PSGs



Rationale

- Local cleft teams are usually the main conduit to patients/families.
- Cleft teams are key in the delivery of cleft care.
- Only 1/3rd of survey respondents were aware of a recognized local support group.

Note: PSGs can enhance cleft team outcomes by improving family/patient investment in care plans over time. They can also be a great resource for the cleft care team in raising awareness and ultimately broadening the provision of care.



98% of healthcare professional respondents believe that support groups can improve the lives of children with cleft.



RECOMMENDATION

#2



Recommendation

Create awareness amongst families affected by cleft of the ways in which PSGs can improve care.



Rationale

- Patients and their families are often unaware of their unique and potentially important role in supporting local cleft teams.
- Peer connections provide emotional and practical support in navigating cleft care.

Note: Respondents highlighted the advantages of PSGs, especially in orienting new mothers, in cleft nutritional support, and in the sharing of personal journeys.



It helps to understand more about clefts and assisting my child to have self-confidence.



RECOMMENDATION

#3



Recommendation

Provide a step-by-step guide on how to initiate a PSG.



Rationale

PSGs are often driven by passionate parent volunteers. They can be challenging to both get off the ground and sustain. Informal, social media-rooted groups are easier to start, but may lack the accountability and formal structure of an officially recognized entity.

Note: Identifying a coordinator/champion to drive the process forward is a good practice.



More than three quarters of those connected with a support group said their group received no funding.



RECOMMENDATION

#4



Recommendation

Cleft teams and PSGs can work together to fill gaps in the provision of care.



Rationale

Established PSGs can provide embryonic groups with valuable insights on group sustainability. The most effective PSGs have clear goals and action plans which are agreed upon with the local cleft team.

PSGs can have a role in identifying service gaps that parents and patients experience. Working closely with the cleft team, PSG volunteers may also contribute to closing these gaps.

Note: In some LMIC contexts, challenges with feeding and proper nutrition are areas where a PSG can help ensure information reaches the families who need it most.



We want to improve our support strategies to be able to have better impact in our community.



RECOMMENDATION

#5



Recommendation

Sustain peer support via online resources and communication hubs.



Rationale

Access to an ongoing online, multilingual 'PSG 101' resource would be a benefit in many LMICs. The ability to share information and to download toolkits would be a welcome asset.



100% of current patient group respondents are interested to connect with other cleft support groups.





NEXT STEPS

The recommendations are aimed at improving awareness about the effectiveness of Parent and Patient Support Groups (PSGs) for families affected by cleft from a wide variety of contexts. Whether you have already organized a support group with the involvement of a cleft care team, or your group of volunteers is seeking to start a group, we hope that these recommendations will spark sustainable progress!

In the future, we are enthusiastic about piloting initiatives to grow PSGs across LMIC contexts. We also welcome further research into the impact of PSGs upon local cleft care teams' patient outcomes.

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Additional Resources

Click to access the following

[Solutions Group 2 Roundtable Recording](#)

[Key Components of a Thriving PSG](#)

[Patient-Centred Care](#)

[Parent Contact Handbook](#)

clapa.com

clefftfriends.co.za

smilefoundationsa.org

clapam.org.my





Solutions Group 3

S4CCC Guideline Series:

INTEGRATING PSYCHOSOCIAL CARE ACROSS CLEFT SPECIALITIES

Propelling Learning Through Collaborative Research
May 2023



CONTEXT

What is “Psychosocial Care”?

Psychosocial refers to “an individual’s social, cognitive, and psychological development in interaction with their environment”. Psychosocial care is support given to help meet the mental, emotional, social, and spiritual needs of patients with cleft and their families.

Why is psychosocial care important to LMIC CCC teams?

Studies suggest that persons with cleft are likely to be viewed differently and may experience social impediments. Individuals with cleft often have some form of facial anomaly or scar which may limit their social interaction and may prevent them from reaching their full potential.

Unhelpful beliefs about cleft in some LMIC contexts may represent an additional limitation to be overcome. Furthermore, families may experience difficulty in accepting their child in light of community stigma about their baby’s condition.

How did we develop these recommendations?

A diverse group of 11 cleft professionals participated in a 3-month research ‘sprint’ that included a global survey that was completed by 130 cleft professionals from 39 countries. These recommendations were presented and discussed at the March 2023 S4CCC Conference.

RECOMMENDATION

#1



Improve Awareness of Cleft Stigma and Community Knowledge about Cleft



Rationale

Cleft conditions may not be widely understood in many Lower Middle Income Country (LMIC) contexts. The prevalence of stigma and myths about cleft can delay or discourage families from seeking treatment. Social stigma can also create tension between parents and limit the self-esteem of patients themselves.

Raising awareness about cleft can take the form of social media posts, radio advertisements, community outreach, and visiting schools to work with teachers and fellow students of a patient.

Cleft community awareness initiatives and cleft-informed psychosocial care for patients and families are strategies that can helpfully build upon one another.



"Some parents believe cleft is God's way for punishing them for whatever they did." (Malaysian respondent)

"People come for surgery before marriage and expect improvement in their speech." (Indian respondent)



RECOMMENDATION

#2



Offer psychosocial training to the whole cleft team



Rationale

Every member of the team can benefit from standardized training by a psychosocial professional using an evidence-informed approach. This training should incorporate a focus upon specific roles, defined responsibilities and clear lines of communication within the team.

Publicizing the integrality of psychosocial care within cleft treatment helps to limit community prejudice about accessing this type of support. Psychosocial care also promotes patient acceptance of cleft care plans, reduces risks of abandoning treatment, and limits unnecessary procedures.

Common psychosocial practice standards within CCC teams ensures that psychosocial care is valued for its contribution to improving outcomes, assuring a better quality of life for patients.



61% of LMIC survey respondents pointed to inadequate information/training about psychosocial care.



RECOMMENDATION

#3



Advocate for increased psychosocial care support for patients and families.



Rationale

Hospital management and community leaders must 'buy-in' to the benefit of psychosocial care and bolster its provision. Local government, private and NGO funders can enable the expansion of psychosocial support to patients and families by providing funding for both staff training and the expansion of psychosocial services.

Academic literature highlighting the relevance and importance of psychosocial care may be a useful tool to onboard management and to advocate with funders.

“

"I think administrators and funders need to be more aware of the need for psychosocial care. Good patient outcomes depend on more than just successful surgery, speech, and teeth."

(Respondent from Australia)

"Funding is not available for psychosocial care in resource limited settings." (Respondent from Kenya)



RECOMMENDATION

#4



Engage in psychosocial research & development



Rationale

A lot of work is still to be done in identifying gaps in LMIC patient care to move toward an evidence-informed approach. We are confident that sharing contemporary psychosocial cleft research will generate greater support for psychosocial care and to improve the quality of the treatment provided.

Creating, translating, validating and employing psychosocial screening tools will contribute to the evidence base.

Additionally, identifying linkages between a cleft team's existing tools for assessing outcomes and psychosocial tools will facilitate the training of clinicians. Some tools are currently limited to one discipline or region of the world but they may have applicability in other fields or regions.



The survey revealed that there are not any standardised psychosocial screening tools, nor standardised training commonly available for cleft psychosocial care in LMIC contexts.





NEXT STEPS

The Roundtable made it clear that effective psychosocial care requires a team effort. Having a single practitioner working in a silo should not be any team's goal. Psychosocial care should motivate parents and patients to adhere to treatment, attend, and actively participate in their appointments.

Psychosocial care begins with parents as early as the cleft is detected and continues throughout treatment. The choice of words and actions by clinicians from the moment of birth is a component of psychosocial care. Psychosocial care both reduces unnecessary surgeries and contributes to the effectiveness of care plans.

This document is intended to provide recommendations that facilitate psychosocial integration into team based cleft care. It can serve as a starting point for discussions within your team, with hospital management, or with funders

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Additional Resources

Click to access the following

[Strategies to Integrate Psychosocial Care](#)
[Improving the Quality of Psychosocial Care](#)
[Facilitating Positive Psychosocial Outcomes](#)
[Upskilling Psychological Care](#)
[Assessing Psychosocial Care and Appearance](#)
[Solutions Group 3 Roundtable Discussion](#)

