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International Consortium for Health Outcomes Measurement

Whitepaper:

Implementation of the ICHOM Standard Set for Cleft Lip and/or Palate Across Four Centers

Authors:

Jessily P. Ramirez[1], EPHM, IMPH; Carolyn R. Rogers-Vizena[2], MD; Maarten J. Koudstaal[3],[4], MD, DMD, PhD; Alexander C. Allori[5], MD, MPH; Petra Peterson[4], MD; Sarah L. Versnel[6], MD, PhD; Inge Apon[3], MD, MHS.

Corresponding Authors:

Jessily P. Ramirez, EPHM, IMPH; I. Apon, MD, MHS.
email: jessily.ramirez@childrens.harvard.edu; i.apon@ichom.org / i.apon@erasmusmc.nl

www.ichom.org/portfolio/cleft-lip-palate

Contents/affiliations/acknowledgements

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Affiliations:

1. International Consortium for Health Outcomes Measurement (ICHOM), Boston, Massachusetts, United States of America.

2. Boston Children's Hospital, Boston, MA, USA and Harvard Medical School, Boston, MA, USA

3. Department of Oral and Maxillofacial Surgery, Erasmus University Medical Center, Rotterdam, The Netherlands.

4. Department of Craniofacial Surgery, Karolinska University Hospital, Stockholm, Sweden

5. Duke Cleft & Craniofacial Center, Duke Children's Hospital; Durham, NC, USA; and Duke University School of Medicine; Durham, NC, USA

6. Department of Plastic and Reconstructive Surgery, Erasmus University Medical Center, Rotterdam, The Netherlands

Acknowledgements:

Introduction

Cleft lip and/or palate (CL/P) is a common congenital anomaly that involves malformation of the lip, dental arch, palate, facial skeleton, and nose, resulting in functional problems related to speech, hearing, eating, and breathing. Children with CL/P require specialty care delivered in stages ranging from birth through young adulthood. To meet these complex needs, comprehensive care is best provided by a multidisciplinary team.

For a cleft team to provide the best care possible — or to identify areas for improvement — it first must have a way to appraise its performance. Explicit measurement of holistic health outcomes enables health systems to prioritize resources on the outcomes that matter most. It is desirable that the outcome measures used by each team are standardized, such that a team may compare its performance relative to that of peer institutions, providing a better frame of reference for what the results mean.

In 2014, the International Consortium for Health Outcomes Measurement (ICHOM) convened a Working Group of 28 multi-disciplinary clinicians, academicians, and patient/family representatives from 8 countries, in order to create a set of standardized outcome measures for cleft teams. Over the course of the next year, the working group developed the ICHOM Standard Set for Cleft Lip/Palate Care[1], which provides guidelines for the outcome domains, specific outcome measures, phenotypic and demographic variables, and timepoints that should be used in the comprehensive assessment of cleft care (Figure 1). The Standard Set was designed with an emphasis on what matters most to patients and includes patient-reported outcome measures (PROMs). It was designed to be practical for implementation (fitting into routine clinical workflows), sustainable in the long-term, and adaptable to meet future needs.

After preparation of the Standard Set, four cleft teams piloted implementation [7]:

- **Boston Children's Hospital (BCH) Cleft and Craniofacial Center** (Boston, MA), where Dr. Carolyn Rogers-Vizena leads the implementation efforts under the continued guidance of Dr. John Meara.

- **Erasmus University Medical Center (EMC) Cleft Team at Sophia Children's Hospital** (Rotterdam, The Netherlands), where Dr. Maarten Koudstaal, previous team lead, with Dr. Sarah Versnel as the current team lead, implemented the Standard Set in routine clinical practice[2].

- **Duke Cleft and Craniofacial Center at Duke Children's Hospital** (Durham, NC), where Dr. Alexander Allori leads the implementation efforts[3].

- **Stockholm Craniofacial Team at Karolinska University Hospital** (Stockholm, Sweden), under the leadership of Dr. Petra Peterson with support from Dr. Koudstaal.

The purpose of this whitepaper is to share what these four teams experienced during their implementation processes. Key lessons for successful implementation relate to organizational "culture change", health information technology, and adaptation of clinical practice and workflow.

Figure 1: ICHOM CL/P Wheel

This wheel captures ICHOM's CL/P recommended minimum set of outcomes

ICHOM CL/P Timepoints

This figure captures the suggested timepoints for the set's PROMs and CROMs

○ Baseline Patient-Reported Form
○ Baseline Parent-Reported Form
□ Baseline Clinical Form
◇ Baseline Administrative Form
▨ Post-Operative Clinical Form
◆ Post-Operative Administrative Form
■ 3 Month Clinical Form
● 5 Year Parent-Reported Form
■ 5 Year Clinical Form
● 8 Year Patient-Reported Form
● 12 Year Patient-Reported Form
● 12 Year Parent-Reported Form
■ 12 Year Clinical Form
● 22 Year Patient-Reported form
■ 22 Year Clinical Form
◆ 22 Year Administrative Form

Timings

We encourage measurement according to the time points included in the above table. Recognizing that different countries have established practices and may take time to transition to these time points, we have agreed age categories for measurement that fit around the recommended specific ages:

3 months: +/- 2 weeks
5 years: 4-6 years
8 years: 8-9 years
12 years: 10 - 12.5 years
22 years: 22 years or end of treatment, whichever is soonest.
Post-operative period: 30 days following the date of the operation

Example Questions from the CLEFT-Q (Psychological Function Scale)

Question	Response Options
Example 1: I feel confident	1 = Never 2 = Sometimes 3 = Often 4 = Always
Example 2: I feel good about how I look	1 = Never 2 = Sometimes 3 = Often 4 = Always

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Organizational transformation

Change management at all organizational levels is crucial for successful implementation. Specifically, this includes:

- Securing support from institutional leadership
- Aligning and motivating all stakeholders involved in the project
- Securing on-going financial and technical support

Securing support from institutional leadership

Endorsement of outcomes measurement by top leadership is key for securing the necessary financial and technical support for implementation. It also helps foster alignment across all parties affected by the transformation (e.g., clinicians, administrators, and patients).

In all four institutions featured here, departmental and hospital leadership prioritized the creation of the ICHOM Standard Set from the start with the aim towards implementation once the Standard Set was finalized. The support from administrators that believed in the project was crucial in providing motivation and financial and administrative support needed for this work.

For example, in 2017, the board of Karolinska Hospital made implementation of all available ICHOM Standard Sets a key initiative. Similarly, at Erasmus University Medical Center, implementation of the Standard Set was part of a five-year strategic plan to transform the institution into a center for innovation in value-based healthcare (VBHC). Dr. John Meara, plastic surgeon-in-chief at Boston Children's Hospital served as ICHOM's Working Group Chair for the development of the Standard Set and was keen to see it implemented locally. He engaged

the support of Boston Children's Chief Executive Officer, Chief Medical Officer, and Information Technology leadership from the beginning of the implementation effort. Similarly, Dr. Alexander Allori, who served as an ICHOM Research Fellow and co-director of the Working Group during development of the Standard Set, was able to convince the director of the Duke Cleft & Craniofacial Center that Duke should be one of the pilot sites for implementation.

Aligning and motivating all stakeholders involved in the project.

The implementation of outcomes measurement affects many aspects of clinical care. In particular, it requires changing clinic workflows, as is discussed below. Cleft care requires multiple interventions and long-term follow-up by an interdisciplinary team. So, garnering the endorsement and support of clinical leaders such as department chairs across all of these disciplines is critical for success. These leaders should be engaged in the project from the very beginning so that they can develop a sense of personal investment and ownership in the project. Support from hospital leadership can also facilitate this.

Early on, along with garnering the support from institutional leadership, the four teams communicated their vision to staff and others affected by the implementation process. The team leaders explained that the project mission is to better understand their clinical performance and discussed how collecting PROMs provides important data for understanding outcomes that matter most to patients, while focusing their discussions as a care team. They also highlighted how outcomes measurement

> "
> *The time investment at the beginning is critical for making sure that all stakeholders not only endorse the project, but also feel a sense of ownership of the project. That's the only way for the project to be accepted, cherished, and sustained over the course of the years."*
>
> Dr. Allori, Duke

could position centers to succeed in new performance-based reimbursement models as well as create a culture of increased ownership of results and satisfaction within the team.

Each team had the following members in their interdisciplinary cleft teams:

- Speech pathologist
- Maxillofacial surgeon
- Plastic surgeon
- Otolaryngologists
- Psychologists
- Orthodontist
- Specialized Nurse
- Clinic Coordinator
- Pediatric Dentist
- Audiologist
- Clinical geneticist
- Pediatrician
- Obstetrician/Gynecologist

Moreover, each implementation team had a core team that was composed of an IT specialist, Project Lead, Academic Researcher, Cleft Surgeon, Clinic Coordinator, and Administrator. In some cases, one person fulfilled multiple roles, for example a cleft surgeon also acted as the project lead.

Managing change takes time and requires sustained levels of motivation and commitment from all stakeholders. As John Kotter recommends in his book *Leading Change*[4], significant changes in culture and process requires frequent reminders of the purpose for the change as well as celebration of early wins. Early on, the Project Leads invested significant time in change management – especially allaying fears of how the new processes might affect daily work, such as creating more documentation burden that would slow down the clinical workflow during a busy clinic day. Also important was explaining how every member of the team could get involved in utilizing the new data to improve team care. The Duke Team was responsive to early stakeholder feedback as the process unfolded, clarifying and improving the user interface of the data-collection platform whenever necessary. When the team coordinator asked if the outcomes data-collection system could also keep track of appointments and attendance, the implementation team built an extension to the project that could facilitate team administration. This allowed the team coordinator to use the system to identify risk factors for "no shows" (missed appointments) and to implement a rapid quality-improvement project that remedied the situation. These kinds of successes helped reinforce the value of measuring outcomes and sustain engagement across the cleft team.

Securing on-going financial and technical support

While implementing outcomes measurement projects, teams will be faced with questions about who funds and delivers each component of the implementation process, especially since funding for outcomes measurement in cleft care is limited. Currently, the four cleft centers that are represented here fund their work through a combination of private grants, government funding, and institutional budgets. Although outcomes can be collected using pen and paper, to have a "real-time" picture of performance for use in quality improvement initiatives and for future benchmarking initiatives, an early investment in IT is necessary.

> "
> *If you have to use pen & paper, the risk of losing data is of course higher and it will be more difficult to do follow-up. Still, it is better to start collecting data and then ask for funding to analyze it later on."*
>
> Dr. Peterson,
> Karolinska

> "
> *In general, expect the implementation to take more time and resources than initially contemplated. If finances, or not exceeding a certain budget, will preclude the team from collecting the data, perhaps opt for a lower tech solution."*
>
> Dr. Rogers-Vizena,
> BCH

In addition to the initial investments in IT infrastructure required for outcomes measurement, it is also important to consider the cost of employees' time on the project. This includes everything from the time that the core implementation team spends on the project to the additional time administrators and clinicians spend with patients to collect and review the outcomes data. Opportunity costs can arise when reallocating staff time to support the project or decreasing the number of patients seen per clinic visit to allow time for the collection and review of outcomes data. This is where securing commitment from organizational leadership, cleft team members, and supporting staff is central to ensuring the long-term success of the project.

# Transformation In Health-Information Technology (HIT)

What platform will be used to collect PROMs? Should outcomes data be stored in the EHR or separately? Should data platforms be built in-house or purchased from an external vendor?

These are the key information technology considerations when implementing outcomes measurement. Each approach offers unique advantages and challenges, which depend on the ultimate goal or motivation for outcomes measurement and the resources available to accomplish the goal. Regardless of the approach taken, it is important that the ultimate solution minimizes the burden of the end users – clinicians and patients.

At Erasmus University Medical Center, implementation of the Standard Set was funded via a grant from two major health-insurance companies in The Netherlands. A provision of the grant was that Erasmus would help other Dutch cleft teams to implement the Standard Set with the aim of developing a national registry for outcomes benchmarking in cleft care. To ensure standardized data collection across these different cleft teams, Erasmus invested in building its own outcomes collection and visualization platform, which was then made available free of charge to other implementing hospitals. In addition, since outcomes measurement is part of Erasmus's strategic mission, it made sense to invest resources in building a platform that could then be used to capture outcomes for all value-based healthcare projects at Erasmus. The platform is called *Zorgmonitor* (meaning 'Health Monitor') and is developed using a combination of Gemstracker and Limesurvey, both which are survey software's. It interfaces directly with Erasmus's EHR and includes clinician-specific and patient-specific dashboards5.

Each column represents a timepoint (0, 5, 8, 12 and 22 years) for the collection of case-mix variables and clinical outcomes (indicated by 'staff') and/or patient-reported outcome measures (indicated 'parents/caregivers'). Green buttons indicate the measurement has been completed and can be viewed, whereas the yellow measurements are still open for completion. Red buttons represent time for completion has expired. Blue buttons

Figure 2: Erasmus University Medical Center's Data Collection Tool.
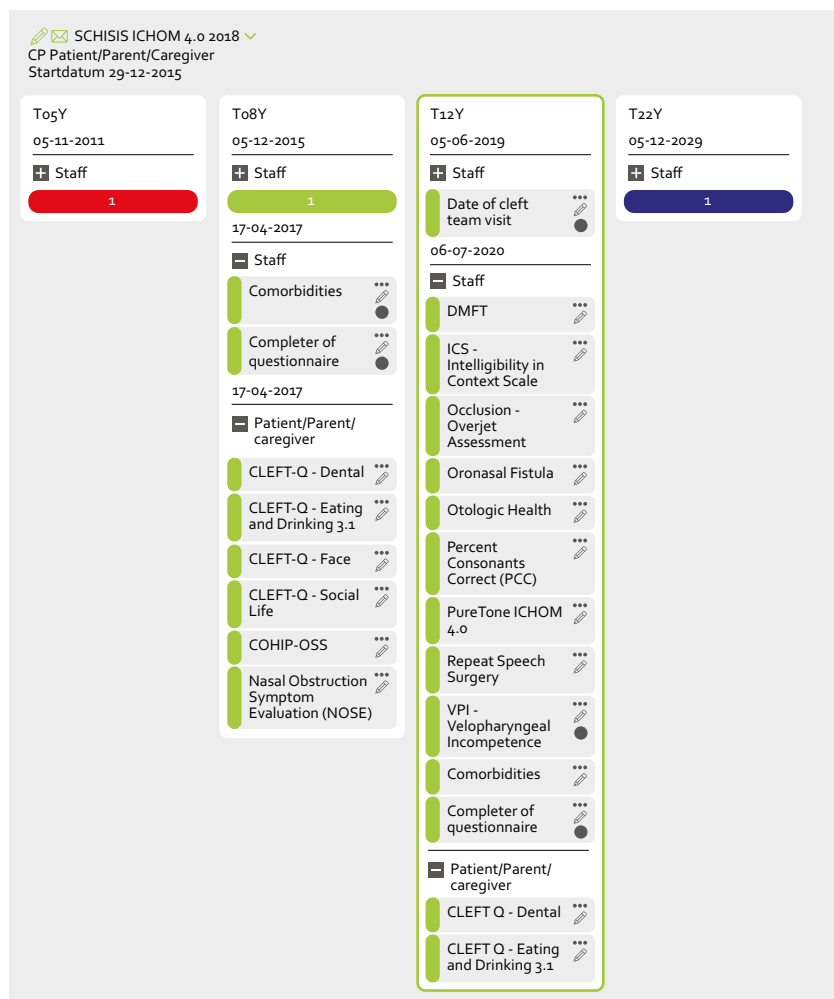
will open for data completion in the future. Extra buttons per surgical procedure including post-operative complications can be added when indicated.

Similarly, implementation of outcomes measurement was considered a key priority by top leadership at the Karolinska University Hospital. So, after piloting data collection using pen and paper, the hospital contracted a third party vendor to build an outcomes collection and visualization platform called *Webformulär*. Like the platform developed at Erasmus, it interfaces directly with Karolinska's EHR.

Boston Children's Hospital used a phased implementation approach. Dr. Rogers-Vizena, who led the initiative, first worked with the team's QI lead to engage the various cleft care specialties and develop a core interdisciplinary team. Next they focused on implementation of PROMs measurement in clinical care. After facing challenges in trying to integrate an external PROMs measurement solution with the hospital EHR, they chose to capture PROMs using REDCap because it is easy, flexible and cost-effective. In addition to capturing PROMs data in-clinic, the team also developed "red

flags" for PROM scores. PROM surveys are administered by a research or QI assistant on an iPad during a clinic visit. If a patient's scores indicate a concern, the "red flag" is triggered and the assistant alerts the team's social worker or other relevant clinician who then evaluates the situation and schedules further consultations when necessary. Once the team felt confident in the PROMs implementation, they turned their focus to collecting the clinician-reported measures.

Implementation at Duke Children's Hospital started a year later than at Boston Children's and Erasmus. As a result, their implementation team had the opportunity to learn from the other teams' experiences. Also, in contrast to Boston Children's and Erasmus, which implemented the Standard Set as quality-improvement projects, Duke chose to implement the framework as a research project. Doing so required more

work (informed consent from patients and/or caregivers, continually updated IRB protocols, and data-transfer agreements (DTA)) but would permit easier integration of the new data into existing research activities. Research funds were limited, so technical solutions for data capture analysis needed to be affordable, practical, and easy to maintain. Dr. Allori chose REDCap as the exclusive platform to organize and run the entire project. REDCap offered several advantages: (1) it is open-access and free to use; (2) it is well-known to researchers and regulatory agencies; (3) it has an adequate and flexible feature set for database and questionnaire development; (4) it has very robust versioning and security features – crucial for safeguarding protected health information (PHI); and (5) usage of REDCap lends itself toward agile development practices – by freeing the project from the

constraints of the EHR, the team could iterate on the design very quickly. Agility was very important, as ICHOM had worked on a few early revisions in the Standard Set (from version 1.0 to 2.0, 3.0, 3.4, 4.0, and 4.1 between 2015-2018), and with every revision, the project would need to be updated to remain compliant with the standards. Being able to adapt this process directly, eliminated extra time, cost, and even effort and frustration.

The unique motivations and IT constraints of the four organizations shaped the way each team developed technical implementations of the Standard Set and workflows for data collection. Each approach was ultimately successful because it respected the needs of the various clinical disciplines involved in cleft care and was designed to optimize local workflow.

Figure 3: Duke Children's Hospital Dashboard

The radio buttons show available outcomes measures from infancy through 22 years of age. The filled buttons show when data were collected – in this simulation, team and surgical data at years 0, 1 and 2; clinical and caregiver data at 5 years; and clinical, caregiver, and patient-reported data at 8 years. Partial data collection occurred at age 10 years. The "purple heart" ages represent the required data-collection timepoints for ACCQUIREnet (Allied Cleft & Craniofacial Quality-Improvement and Research Network). The team may optionally measure outcomes in other years.

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Transformation in workflow and clinical care

Outcome measurement requires significant changes both to how a clinic is run – the workflow – and the role of the patient in their own care. All four teams noted how these changes:

- Affect clinic operations or workflows
- Highlight the need to educate patients and families about the role of outcomes measurement in their care.
- Serve as a catalyst for increased collaboration between clinical disciplines and clinic staff.

Effects on clinic operations or workflows

The Standard Set details the specific outcomes and case-mix variables that need to be collected (the "what" of data collection) and the timepoints for data collection ("when"). But it does not prescribe the "how" or "who" of data collection, as the Working Group knew that this would vary across organizations and cleft teams. Given the highly multidisciplinary nature of cleft care, the "who" (i.e., who should measure the outcome and record the data) warranted special consideration. For example, a dentist, orthodontist, and oral-maxillofacial surgeon are all appropriate for measuring *Dental Health* using decayed, missing, and filled teeth (DMFT) index scores; similarly, both a psychologist and social worker may administer CLEFT-Q subscales (social, school and psychological) to measure sociometric and assess *Psychosocial Functioning*. It is important to figure out which of these specialists should be assigned the responsibility to do so for standardized, prospective data collection.

To craft an approach that would work best for their teams, all four implementation directors started out by mapping current clinic workflows. This provided the necessary information to determine who needed to be involved in data collection and agree on new workflows that allowed for reliable data collection. Each of the implementation teams then piloted the new workflows and noted the additional time needed to allow for outcome measurement.

For example, Duke started by collecting outcomes data on paper forms. Cleft team members were instructed to collect the data (filling out the paper forms) on a few patients each week for a short trial period. The bottom of each form had a blank area where each team member could write thoughts, questions, comments, criticisms, suggestions, etc. This early experience was critical to answering the "who" question – who should collect each data element. In Duke's case, this process identified that certain elements assigned to Otolaryngology should be switched to Audiology, and certain elements assigned to Social Work were better worked into the family-reported surveys. After the data-collection workflow had been adequately clarified, the Duke team designed a REDCap-based implementation of this workflow. All team members were trained to use the new system and use it live in clinic, starting first with only one patient per clinic, then two, then four, etc., until they were capturing data on the majority of patients. During this phase, the emphasis

> "
> *In the beginning we had some people argue that it costs a lot of extra time but once you have everything up and running and you're used to a new way of working, it really fits."*
>
> Dr. Versnel, EMC

was on the process of data collection rather than the data being collected. They used this period to identify friction points, create necessary clarifications or workarounds, and retraining staff as necessary. After working out the kinks, the team announced a "go-live" date, which allowed for a practice run, and then began true prospective data collection.

Collection of speech outcomes data has an influence on clinical practice and workflow.

The ICHOM Standard Set requires some speech and audiology measurements that might not traditionally be collected for specific patients at the timepoints outlined by the Standard Set. These cleft disciplines require extra time to collect measurements and adjustments have been made to ensure these outcomes are measured as part of routine care.

For example, the Standard Set measures *articulation* as an outcome of the speech outcome domain, using the Percentage of Correct Consonants (PCC) instrument. At Duke, speech therapists use connected speech rather than isolated speech for clinical evaluation therefore clinicians need to do a different speech evaluation that's not part of their standard clinical practice. This speech consult takes about 5-10 minutes longer as compared to non-data collection patients. To support speech therapists in ensuring this outcome is measured, the Duke cleft team established a norm that these counts had to be included in the patient's record by noon the next day. This allowed more time for speech therapists to complete their counts, measure what matters to patients, and help maintaining the fidelity of the Standard Set variables.

EMC used a different approach. They started out measuring the full standard set – all diagnoses and all ages. To make this manageable, they selected two to five patients per clinic to test the data-collection software until they had experience with capturing all outcomes at all timepoints. Then, they made any adjustments suggested by this experience and then moved to measuring outcomes on the full patient population.

Outcomes measurement as a catalyst for interdisciplinary collaboration

All four cleft teams found that having patients complete PROMs as part of the clinic visit greatly enhanced the quality of their discussions with patients and catalyzed discussions between patients and their families, and between the clinical disciplines represented in the care team. Some cleft teams, such as the team at EMC, noted that measuring outcomes as defined by the Standard Set extended each patient's clinical encounter by a few minutes, which means fewer patients are seen per clinic. However, the benefit of improved communication offset this concern.

For some cleft centers, patients and family members complete outcomes questionnaires in advance of the clinic visit. For example, at EMC and Karolinska, an e-mail invitation to complete PROMs on-line is sent out to patients two weeks prior to their visit. Once patient responses are received, they are visible in the EHR. A nurse specialist generates an overview of each patient's responses. The cleft team then meets right before cleft clinic to discuss each patient, including reviewing their patient-reported outcome measures (PROM's). As a result, the cleft clinicians are able to focus their consultation on the patient's main concerns. The cleft centers that used this approach found that, to ensure completion of the questionnaires at home, patients needed to be educated through discussions with their providers about the importance of this data in their care. This also served as a good way for parents to prepare their children before the clinical visit, where they could explain, discuss and answer sometimes difficult questions in the safe home-environment.

Putting outcomes measurement to work for patients

Collecting PROMs creates an expectation for patients that clinicians will follow up and address the concerns the patient expresses. At EMC, patient reported outcome scores are always discussed during the outpatient clinic visit by a specialized nurse. The nurse gives feedback on the scores and asks more specific questions if an answer raises concern. For example, if a patient's self-reported scores for psychosocial well-being are low, the nurse will discuss whether the patient wishes to have a consult with the psychologist or social worker. Before measuring outcomes based on the ICHOM Standard Set, psychological needs sometimes went undetected. Now, they are intentionally screened and discussed.

One of the CLEFT-Q speech scales in the Standard Set measures speech-related distress and questions "how do you feel about speaking?"6. If a patient shows low marks on this scale, clinicians at Duke use this as a starting point for a discussion with a question like, "I noticed that you answered these questions 'always'. It seems to bother you a lot. Can you tell me more about that?" This invites patients into a conversation so that their needs can truly be addressed.

Although these cleft centers review and discuss outcomes with patients, they are not yet using the data directly in clinical decision making. This is largely due to the lack of data on normative values and cut-off scores for the PROMs included in this Standard Set. EMC is conducting research on how these values should be presented to patients at different ages (young children vs. 22-year-old patients) and whether or not results should be shown against earlier outcome scores, against normative data, or against outcome scores of other cleft populations.

> *The fact that the child doesn't bring it up, doesn't' necessarily mean that it's not an issue. If you don't raise it [as a clinician], you don't know it and you can't help them in a timely fashion. It's important to ask questions, but it's more important to train your team to start the conversation and make sure they know how to deal with the answer, so that they're not afraid of the answer… having the psychologist explaining this to our team, but also if the parents raised this issue, we were able to explain during clinic this is why we're doing it. From research and experience, we know it is better to ask the question than to avoid it."*
>
> Dr. Koudstaal, EMC

Future direction: towards collaborative networks and benchmarking

Comparison of outcomes and benchmarking requires the collection of large, robust datasets that are accurate, complete, and provide a cross-representation of different ages and measurement timepoints. Even more robust datasets are required for risk adjustment across phenotypes, syndromic conditions, etc. The nature of CL/P care presents significant challenges for developing such a dataset. ICHOM's CL/P Standard Set is designed to capture all these outcomes over a large span of time, often with wide time intervals (3 years or more) in between measurements. This presents a challenge for longitudinal data collection. For example, it is not uncommon for patients to transfer their care to a different institution at some point. Therefore, it takes considerable time and collaborative data sharing to develop robust outcomes datasets.

The four teams identified the following challenges to outcomes comparisons and benchmarking:

- Navigating privacy laws that create a barrier to accessing and sharing data, which can exclude teams from benchmarking efforts. This has highlighted the need for pooled analysis and on-site analysis.

- The need to develop protocols to ensure that data is extracted in a uniform format/coding for running pooled analysis across centers.

- The need to develop risk-adjustment models for outcomes benchmarking and best practices or guidelines for performing cohort analyses.

As a result of these challenges, the implementation efforts discussed here have not yet resulted in outcomes comparisons or benchmarking between organizations. However, both Duke Children's Hospital and Erasmus Medical Center are leading regional collaboratives.

Duke Children's Hospital founded ACCQUIREnet - the Allied Cleft & Craniofacial Quality-Improvement and Research Network. It is a multi-site collaborative network dedicated to implementation of the Standard Set as well as multi-site aggregation, benchmarking, and comparison of outcomes. The project is under Dr. Allori's direction. Duke serves as the coordinating center for ACCQUIREnet, as well as the statistical support center for data analysis. The project is registered as an observational study on clinicaltrial.gov (NCT02702869). Presently, six additional American centers have joined ACCQUIREnet, agreeing to collect the ICHOM Standard Set data using the REDCap-based system developed by Dr. Allori. ACCQUIREnet is open for membership to all North American cleft teams.

Similarly, Erasmus University Medical Center is currently the coordinating center for the European Reference Network for rare and/or complex Craniofacial Anomalies and ENT disorders (ERN CRANIO). The network has 29 member hospitals across 11 EU member states. The ERN CRANIO working group for cleft lip and/or palate

agreed to adopt the ICHOM Standard Set as minimal dataset for registering outcomes at ERN CRANIO sites. The ERN registry is under development and will enable data collection across Europe, for the primary purpose of evaluation of quality of treatment, and outcomes research in the future. In order to optimize the set for outcomes research in the different domains, additions and adjustments to the Standard Set are being examined. The goal is to make the database compatible with the ACCQUIREnet database in order to facilitate future collaboration in outcomes research and possibly benchmarking, while respecting privacy laws. Currently, six other Dutch cleft centers are also working to implement the ICHOM Standard Set in their clinical practice. The cleft team at Erasmus University Medical Center is collaborating with these six teams and Dutch Hospital Data (DHD) to develop a national benchmark with uniform collected outcome data. DHD is a foundation that collects, manages, and processes data from hospitals to provide information for decision making management. DHD is developing a secure, on-line dashboard for presenting the aggregated outcomes data from the various Dutch cleft teams. The plan is to hold regular meetings with representatives of each cleft team to compare outcome results, discuss differences and learn from each other. It will also be possible to use this dashboard for quality improvement projects within one cleft team.

It is noteworthy that since both ACCQUIREnet and ERN CRANIO have implemented the ICHOM Standard Set, data collected by sites in these two networks is interchangeable. Already, the cleft teams from Duke, BCH, Erasmus, and Karolinska have rich research collaborations, particularly focused at the moment on optimizing the ICHOM Standard Set. Their observations and recommendations will be shared with the ICHOM Stewardship Committee and Scientific Advisory Council for consideration for future iterative improvements to the Standard Set.

Conclusion

The implementation experiences of these four cleft centers illustrate the different approaches that can be taken to successfully implement outcomes measurement in routine clinical practice as well as some of the common challenges and barriers. Their experiences all highlight the benefits of outcomes data collection for improved communication between patients and clinicians. The hope is that the experiences shared here will inform and encourage others to implement outcomes measurement, laying the groundwork for outcomes comparisons and benchmarking over time.

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List of terms/ abbreviations

ACCQUIREnet: Allied Cleft & Craniofacial Quality-Improvement and Research Network.

BCH: Boston Children's Hospital

CL/P: Cleft lip and/or palate

DHD: Dutch Hospital Data

DMFT: Decayed, missing, and filled teeth outcomes scale

DTA: Data-transfer agreement

EHR: Electronic health record (alternatively, electronic medical record)

EMC: Erasmus University Medical Center

ERN: European Reference Network

HIT: Health-information technology

ICHOM: International Consortium for Health Outcomes Measurement

IT: Information technology

PCC: Percent Consonants Correct

PHI: Protected health information

PRO: Patient-reported outcome

PROM: Patient-reported outcome measure

VBHC: Value-based health care

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BCH Cleft and Craniofacial Center

Email: carolyn.rogers@childrens.harvard.edu

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Duke Cleft & Craniofacial Center

Email: alexander.allori@duke.edu

www.dukehealth.org/pediatric-treatments/
pediatric-plastic-and-reconstructive-surgery/cleft-lip-and-cleft-palate

Erasmus University Medical Center Cleft Team

Email: m.koudstaal@erasmusmc.nl

www.erasmusmc.nl

**Stockholm Craniofacial Team,
Department of Plastic and Craniofacial Surgery**

Email: petra.peterson@sll.se

www.karolinska.se/for-patienter/alla-mottagningar-och-avdelningar-a-o/
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