EOSQ-24: Research Tool or Does it Change my Practice?

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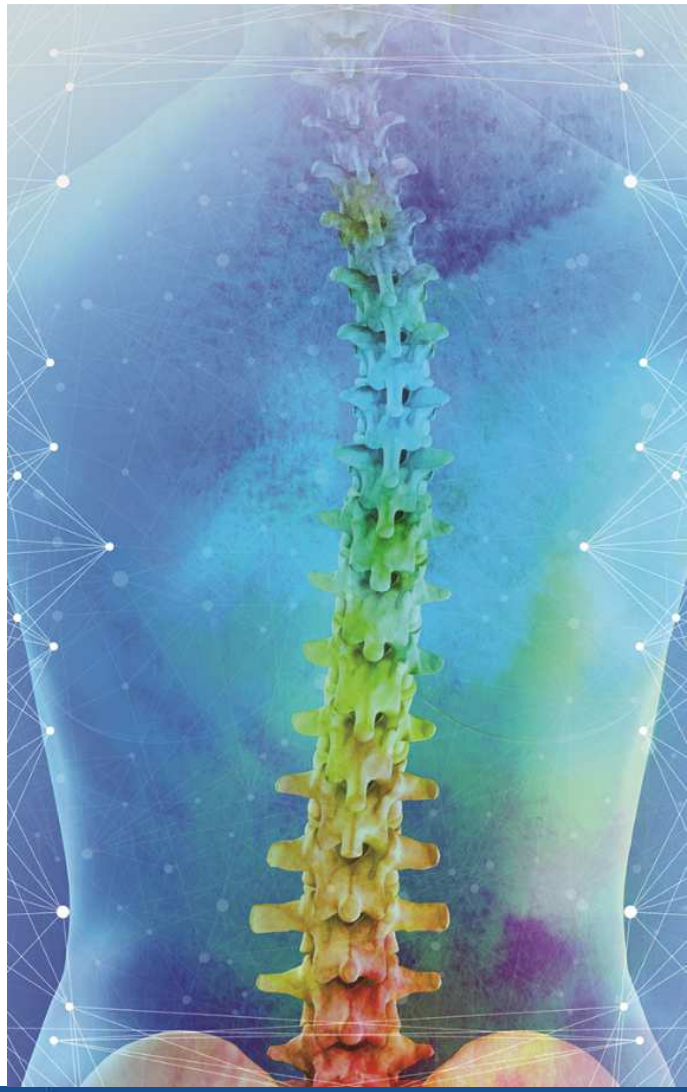
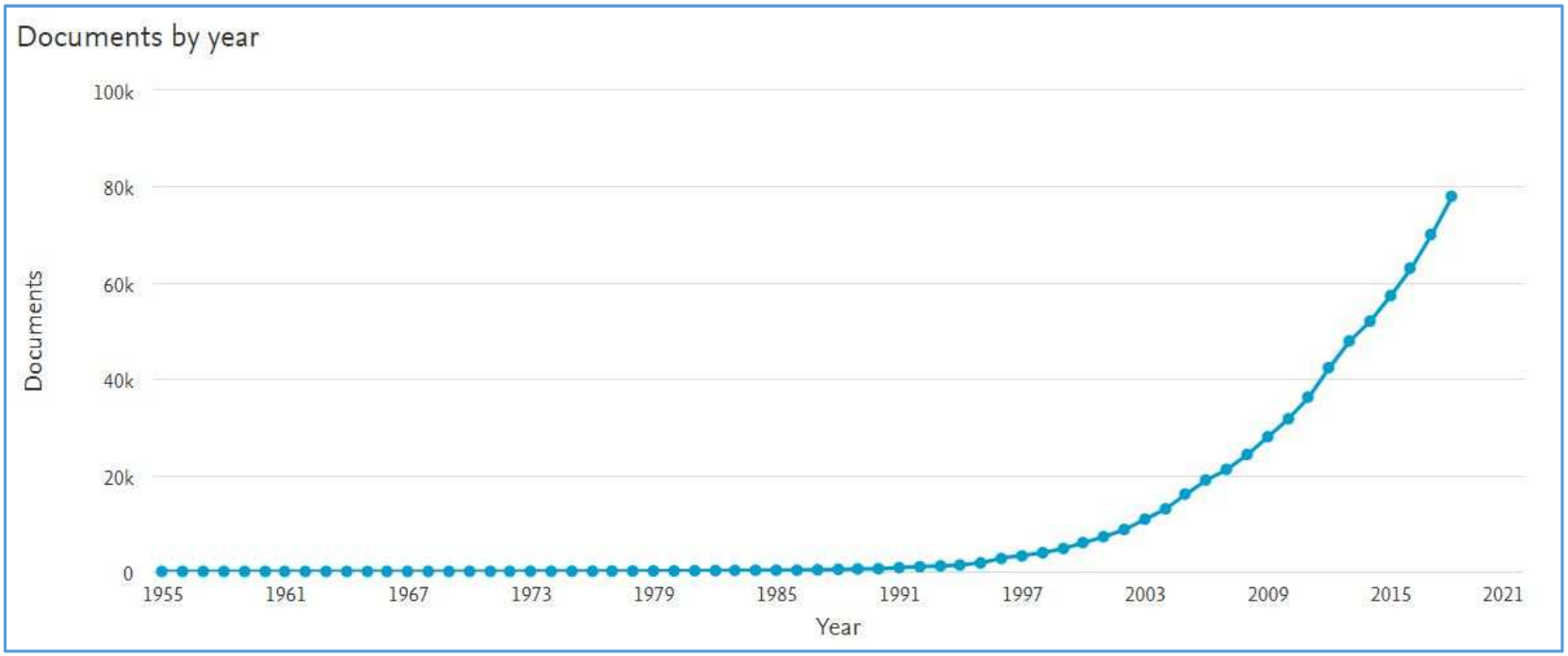


Health-Related Quality of Life

- **Interest in Health-Related Quality of Life has grown exponentially.**
  - Approximately 80,000 documents studied HRQoL in 2018



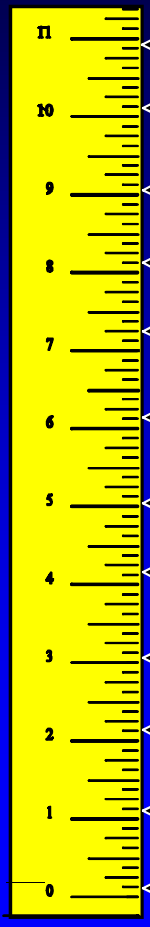
Patient-Based Outcomes in EOS

Difficult to measure

- **Heterogeneous population**
- **Significant comorbidities**
- **Age is variable**
- **Natural history can be subclinical in childhood**

Who are your patients ?

AIS



- **Sports without Limitations**
- Vigorous activities with limitations
- Moderate activities
- Moderate activities with limitations
- Walk slowly
  Trouble bending, stooping
- Need help to bathe
- Cannot maintain balance
- Move about with help
- Stand up with help
- Staying in bed/partly undressed
- **Lying down most of time**
- Confined to room, bed

al of NewYork-Presbyterian
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Measuring Quality of Life in Children With Early Onset Scoliosis: Development and Initial Validation of the Early Onset Scoliosis Questionnaire

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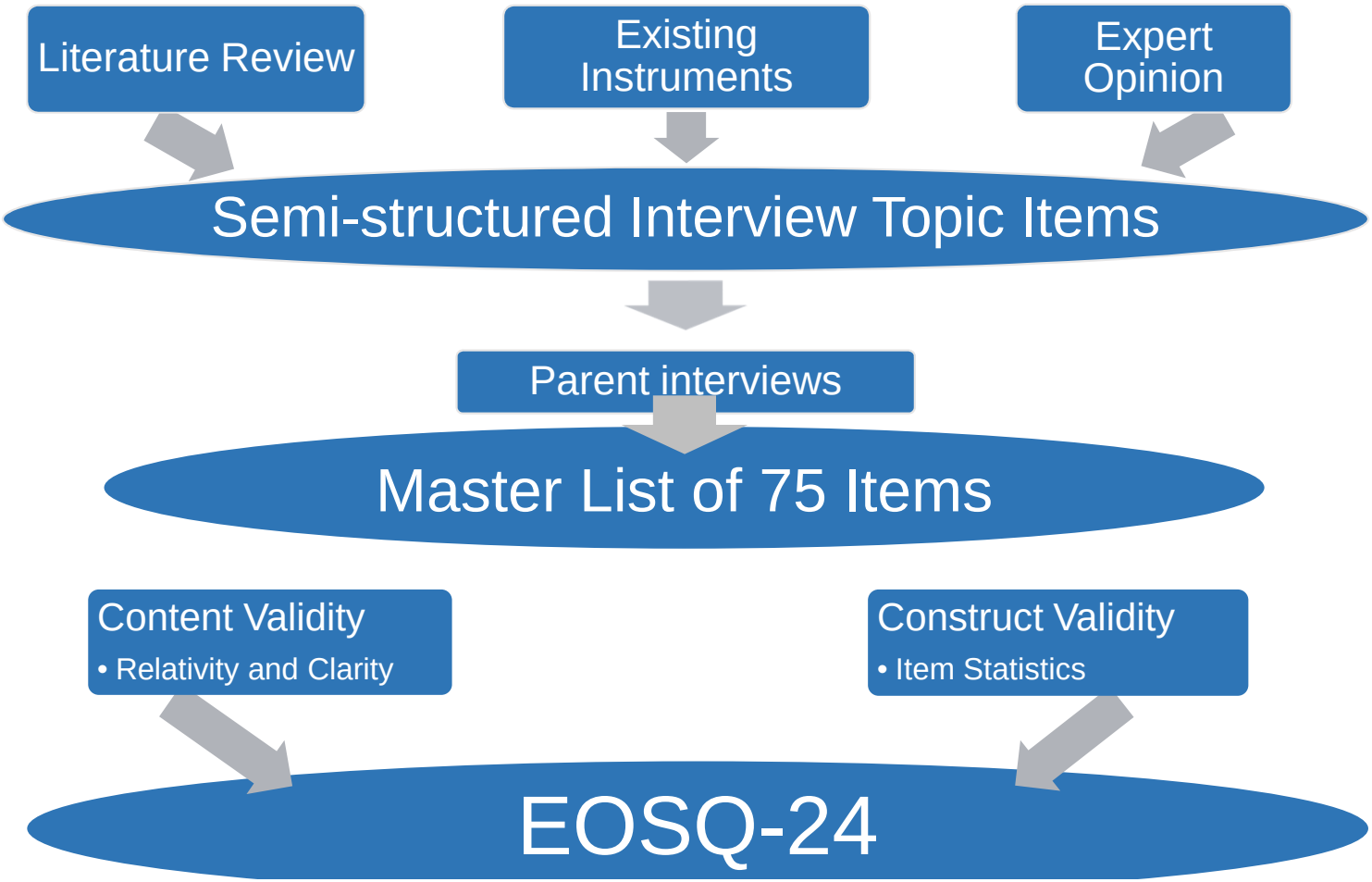
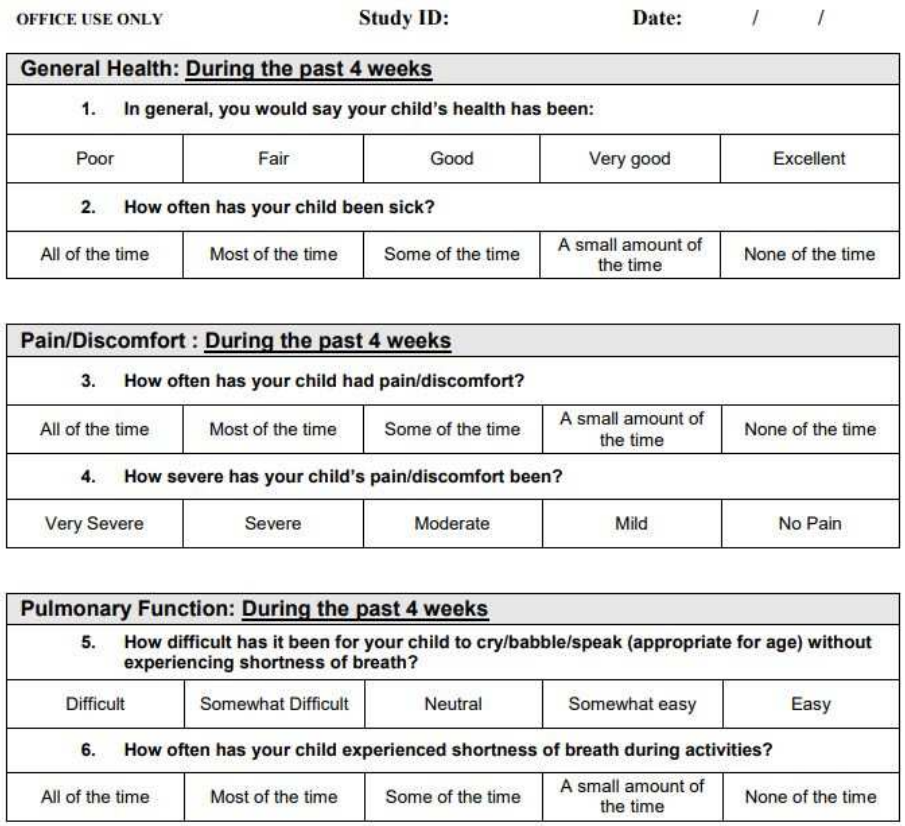
PEDIATRIC SPINE STUDY GROUP



EOSQ-24 Domains

Questionnaire with 24 items, 11 domains

- **Health Related Quality of Life**
  - General Health
  - Pain/Discomfort
  - Transfer
  - Physical Function
  - Daily Living
  - Fatigue/Energy Level
  - Emotion
- **Parental Burden**
- **Financial Burden**
- **Satisfaction**
  - Child Satisfaction
  - Parental Satisfaction



OFFICE USE ONLY Study ID: Date: / /

General Health: During the past 4 weeks				
1. In general, you would say your child's health has been:				
Poor	Fair	Good	Very good	Excellent
2. How often has your child been sick?				
All of the time	Most of the time	Some of the time	A small amount of the time	None of the time

Pain/Discomfort : During the past 4 weeks				
3. How often has your child had pain/discomfort?				
All of the time	Most of the time	Some of the time	A small amount of the time	None of the time
4. How severe has your child's pain/discomfort been?				
Very Severe	Severe	Moderate	Mild	No Pain

Pulmonary Function: During the past 4 weeks				
5. How difficult has it been for your child to cry/babble/speak (appropriate for age) without experiencing shortness of breath?				
Difficult	Somewhat Difficult	Neutral	Somewhat easy	Easy
6. How often has your child experienced shortness of breath during activities?				
All of the time	Most of the time	Some of the time	A small amount of the time	None of the time

EOSQ: 2012-Present

- In clinical and research use since 2012
- Multiple validation studies
- Translated to Turkish, Mandarin Chinese, Spanish, Norwegian, Arabic, Dutch, German
- 17,927 EOSQ-24s administered and entered in PSSG Registry
- 26 publications available on PubMed

EOSQ-24 as a Research Tool

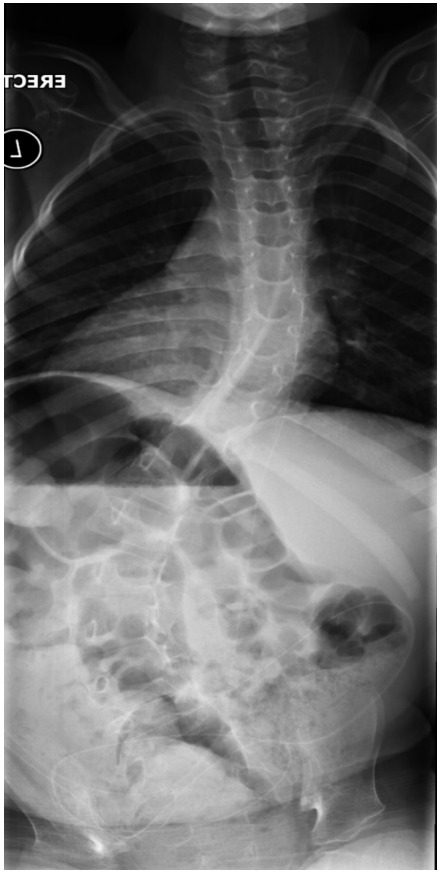
EOSQ-24 is a Disease Specific HRQoL Measuring Tool

- **Measuring HRQoL provides new prospective on new and old questions**
- **Studies using EOSQ-24 have been cited 73 times**

Example Research Questions We've Been Able to Answer:

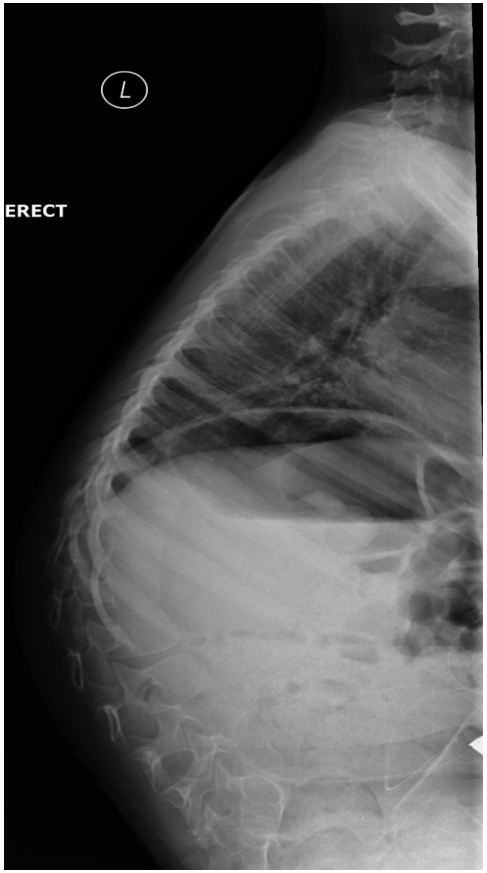
- **Improvement in QoL with conversion from TGR to MCGR?**
- **Difference in QoL for Growing Rod "Graduates" with Severe vs. Moderate EOS?**
- **Does Decreased Surgical Stress Improve QoL?**
- **Difference in QoL for Single Fusion Vs. Growth Friendly Surgery in Older EOS Patient?**
- **Improvement in Pulmonary Function in Patients with SMA After VEPTR?**
- **Many additional abstracts, publications, and ongoing studies…**

Patient JL – 7-year-old girl with SMA Type 2



Patient requires improvement in respiratory status.

- **EOSQ-24 PF Score - 26**
- **EOSQ-24 HRQoL Score - 47**



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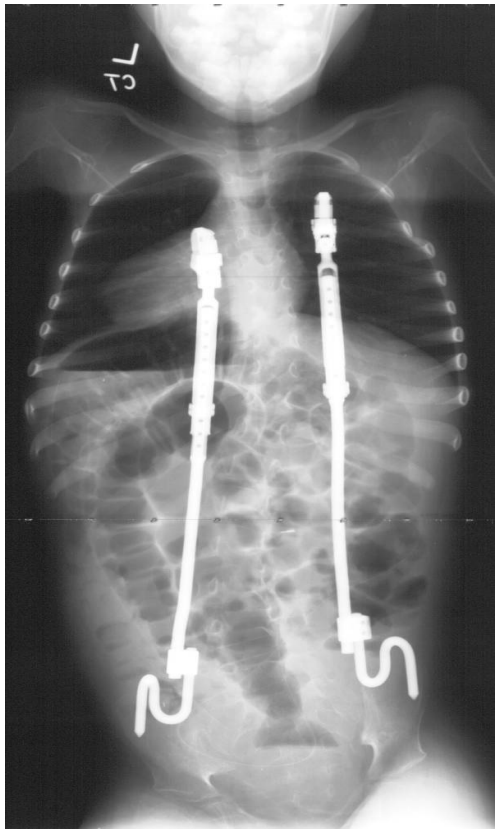


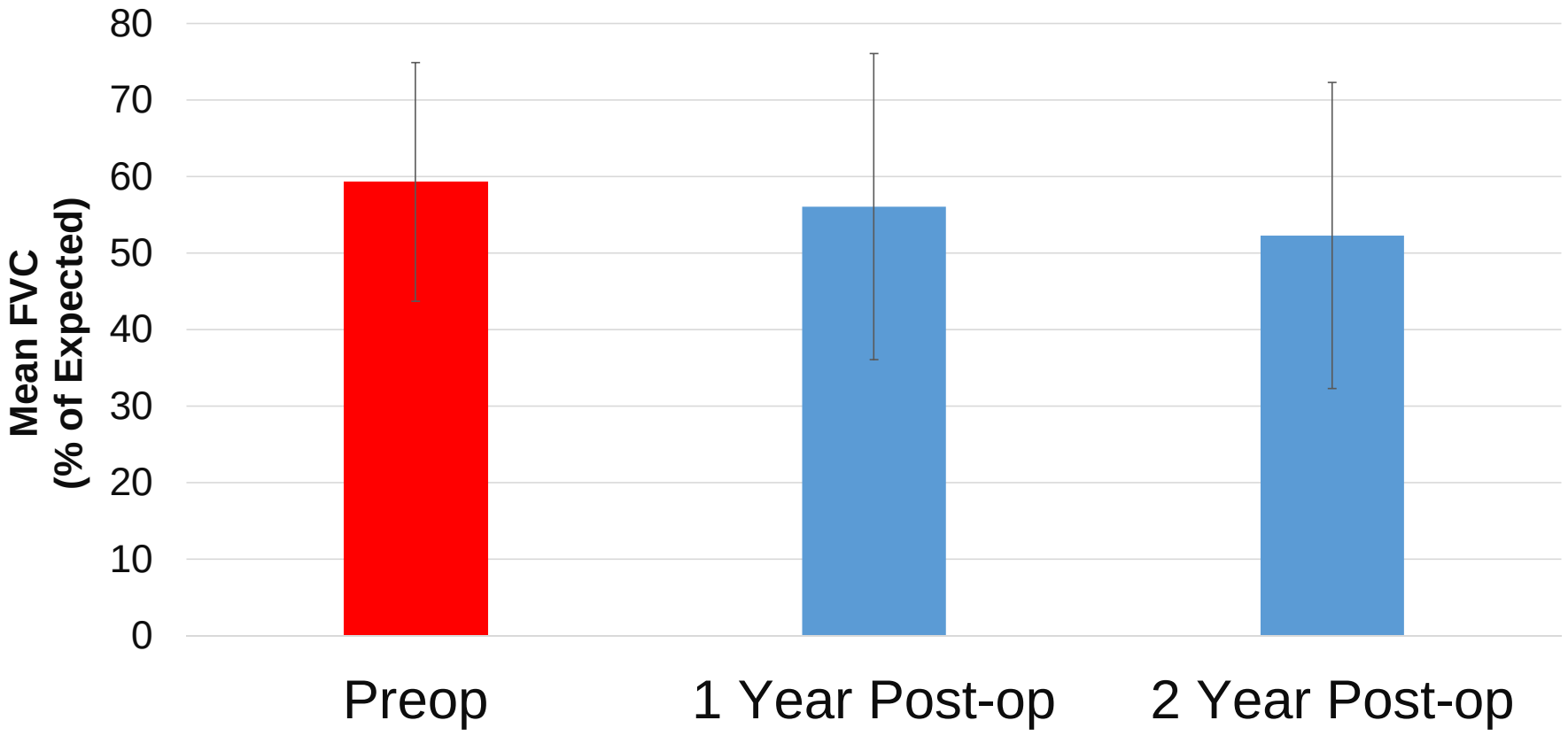
Patient experiences improvement in respiratory status after TGR

- **EOSQ-24 PF Score - 26**
- **EOSQ-24 HRQoL Score – 47**

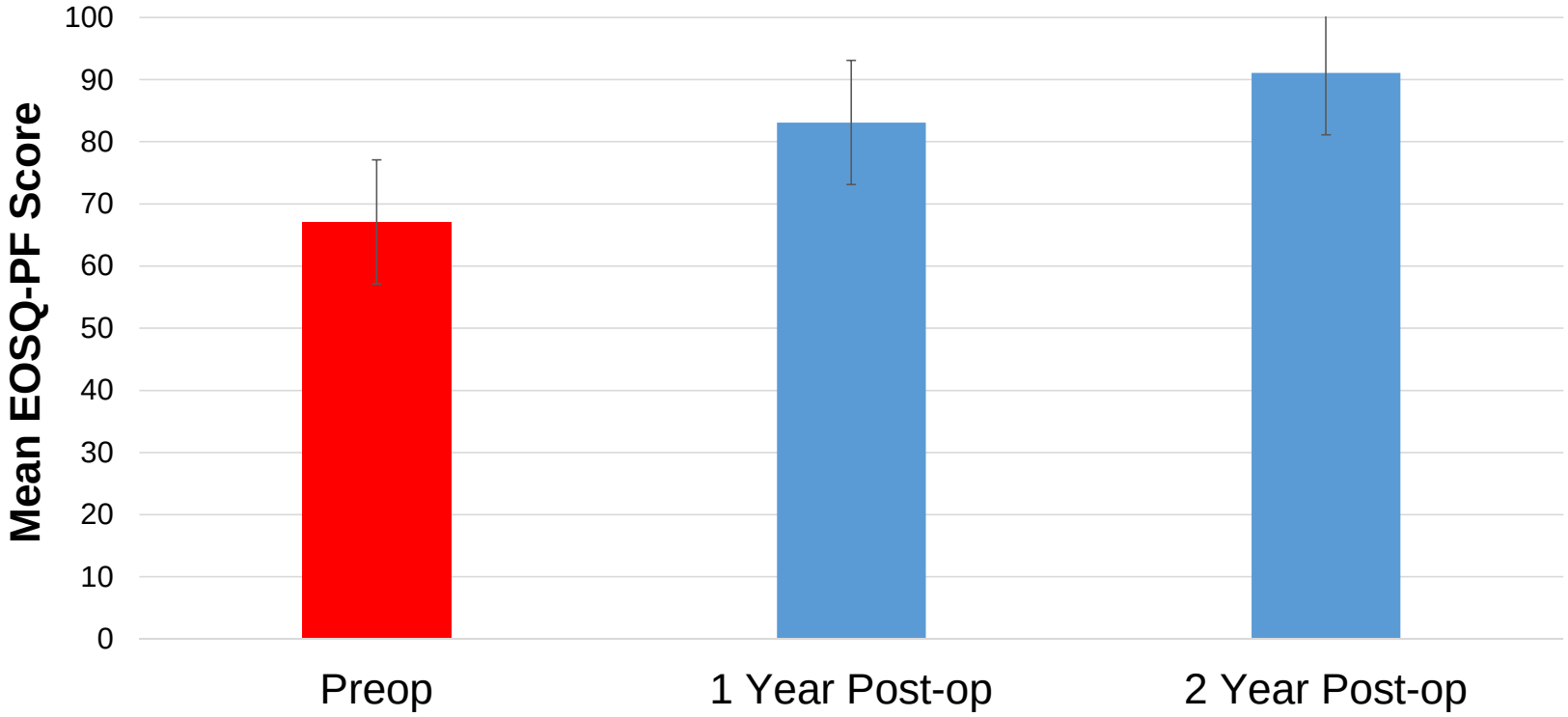
Post-operatively, dramatic improvement in respiratory status.

- **EOSQ-24 PF Score – 53**
- **EOSQ-24 HRQoL Score - 81**

In patients with SMA, Pulmonary Functioning Testing did not increase post rib based growing constructs

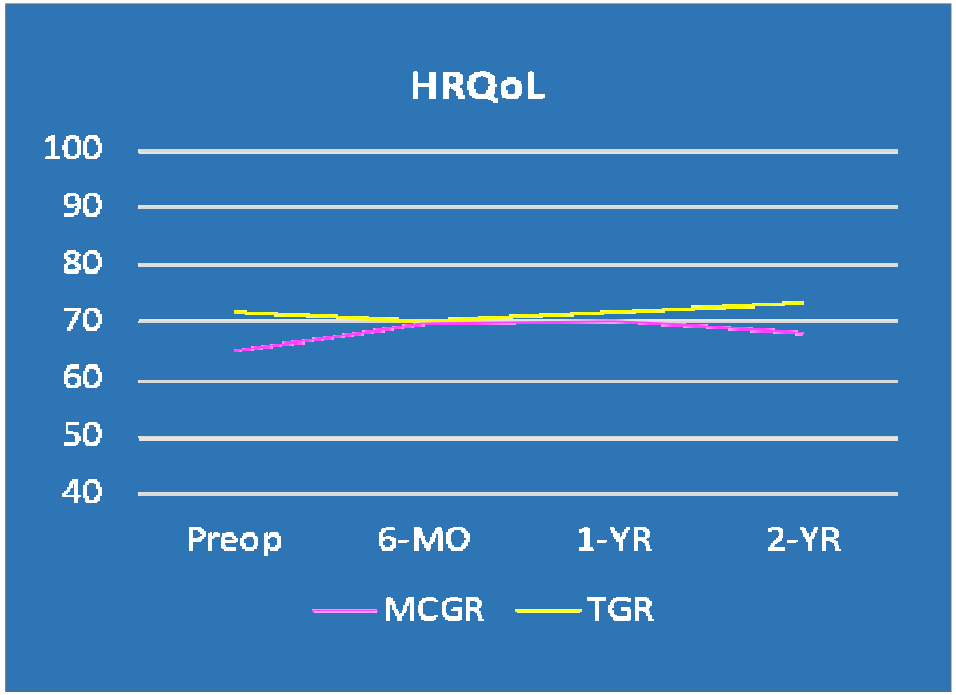


However, EOSQ-24 Pulmonary Function Scores Increased Post-Operatively



EOSQ-24 data can provide quality of life assessments not captured by traditional testing.

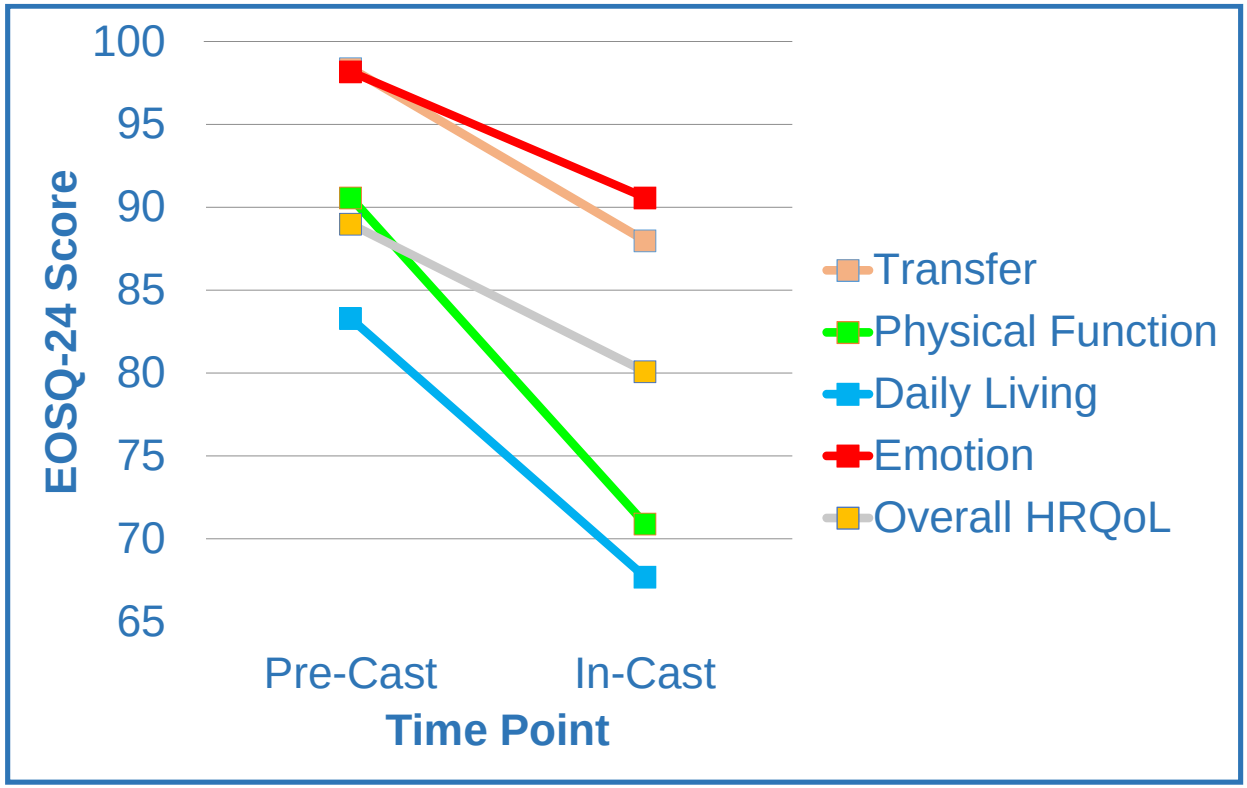
Are HRQoL Measures Similar at 24 Months Between Magnetically-Controlled Growing Rod Patients and Traditional Growing Rod Patients?



No statistical difference with HRQoL for MCGR Vs. TGR at 2-year follow-up

- Is EOSQ-24 missing something?
- Is 2-year follow-up too short?

Idiopathic EOSQ Decline Significantly in 6 Domains While In-Cast



Questions We've Answered With EOSQ-24

Does Unplanned Returns to the Operating Room (UPROR) impact HRQoL?

- EOSQ scores decreased for congenital, neuromuscular, and syndromic EOS patients but not idiopathic etiology.

Does residual pelvic obliquity after definitive spinal fusion impact HRQoL?

- EOSQ scores were negatively correlated with pelvic obliquity only in *ambulatory* idiopathic, syndromic, and neuromuscular patients.

Does HRQoL change for patients after TGR implantation?

- EOSQ scores were unchanged 2-years post-operatively in patients who received TGR.

Does HRQoL change in patients undergoing serial Mehta casting?

- EOSQ scores decrease while in-cast for both idiopathic and non-idiopathic patients.
- Non-idiopathic patients have improvement in QoL after casting while idiopathic remains static.

EOSQ for Adolescents

Current EOSQ-24 measures *parents*' perspectives on their *children's* HRQoL

Goal: To develop a self-reported health-related quality of life (HRQoL) instrument appropriate for adolescents with EOS between 8-18 years of age

Phase I: EOSQ-A

- Phase I – Semi Structured Interview - 12 patients
- 59 item master list of questions developed
  - 14 domains (4 new domains)

- General Health (2 questions)
- Pain/Discomfort (2 questions)
- Pulmonary Function (2 questions)
- Transfer (2 questions)
- Physical Function (7 questions)
- Daily Living (5 questions)
- Fatigue/Energy Level (2 questions)
- Emotion (12 questions)
- Satisfaction (3 questions)
- Sleep (7 questions)
- Appearance (6 questions)
- Relationships (6 questions)
- Family Dynamics (3 questions)

Excerpts of Surveys

Excerpt of Global Assessment Form (GAF) – Completed by Parent/Patient

General Health: During the past 8 weeks						
1. In general, how would say your child's health has changed before and after surgery?						
Significantly worse	Moderately worse	Slightly worse	Neutral	Slightly better	Moderately better	Significantly better
2. How has the frequency of your child being sick changed before and after surgery?						
Significantly worse	Moderately worse	Slightly worse	Neutral	Slightly better	Moderately better	Significantly better

Physician Prognosis Form

4) What is your OVERALL assessment of the change in this patient after intervention? (Check One)

- ☐ Important deterioration
- ☐ Slight deterioration
- ☐ No change
- ☐ Slight improvement
- ☐ Important improvement

5) What is your assessment of this patient's pain/discomfort after intervention?

- ☐ Important deterioration
- ☐ Slight deterioration
- ☐ No change
- ☐ Slight improvement
- ☐ Important improvement

EOSQ for Adolescents – Status and Future

Status:

Currently enrolling for Phase II—Reliability and Validity assessment

- Currently 74 patients enrolled

Phase III – Responsiveness assessment

- Administer before and after interventions

Phase IV – Normative data collection

Preliminary Analysis on Content Validity

Q15) How difficult has it been for you to move your head/neck to use a computer?

Mean Relevancy Score
3.47

Q39) How often does your health condition create problems/issues between you and your girlfriend/boyfriend?

Mean Relevancy Score
2.47

MCID of the EOSQ-24

funded by grant from SRS

- Define the minimal clinically important difference (MCID)
- Traditional assumption has been that a change of 10% in HRQoL scores is the MCID
- 62/80 patients enrolled

SRS-22

Table 4. Calculated Minimum Clinically Important Difference (MCID) Based on Receiver-Operating Characteristic Curve Analysis of Domain Scores

Domain	ROC MCID	AUC	SEM	MDC
Appearance	0.98	0.63 (0.60–0.68)	0.21	0.47
Activity	0.08*	0.65 (0.60–0.69)	0.17	0.41
Pain	0.20	0.72 (0.70–0.77)	0.15	0.33

Standard error of measurement (SEM) and 90% minimum detectable change (MDC) of preoperative scores.
*ROC-determined MCID for the activity domain is smaller in value than both the SEM and MDC.

PROMIS

PRO	Domain	MID
Adult PROMIS	Pain	3.5-5.5
Pediatric PROMIS	Pain	2.0-3.0

Future Directions

- Applying EOSQ-24 Scores to patients and not populations
  - Changing surgical decision making based on outcomes
- Continue studying quality of life outcomes for surgical techniques
- Optimizing time to intervene based on quality of life and radiographic parameters

Don’t be the Blind Man

Thank You!

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PEDIATRIC SPINE STUDY GROUP

AMAZING THINGS ARE HAPPENING HERE for KIDS

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