

# TEXAS CHILDREN'S HOSPITAL PEDIATRIC QUALITY OF LIFE SURVEY - RHEUMATOLOGY

DSRIP Region 3 Learning Moment – July 20, 2016

JaLeen Rogers, MPH

Theresa Anderson, LMSW

Bethany Lowe, MHA

GOVERNMENT RELATIONS AND COMMUNITY BENEFITS



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# PEDIATRIC QUALITY OF LIFE (PEDSQL) BACKGROUND

- Pediatric Quality of Life Survey
  - Measures health-related quality of life (HRQOL) in healthy children and adolescents and those with acute and chronic health conditions
  - Generic Core Scales
    - 23 items
    - Developmentally Appropriate
      - Ages 2-4: Parent Proxy Report
      - Ages 5-7, 8-12, 13-18: Child Self Report and Parent Proxy Report
    - Multidimensional
      - Physical Functioning (8 items), Emotional Functioning (5 items), Social Functioning (5 items), School Functioning (5 items)
    - Reliable (Total Scale Score: 0.88 Child Self-Report, 0.90 Parent Proxy Report)
    - Valid
    - Multiple language translations available (English and Spanish used at TCH)
    - **IRB Exempt for DSRIP purposes**

# PEDSQL SURVEY DOMAINS

- Physical

ABOUT MY HEALTH AND ACTIVITIES (PROBLEMS WITH...)	Never	Almost Never	Some-times	Often	Almost Always
1. It is hard for me to walk more than one block	0	1	2	3	4
2. It is hard for me to run	0	1	2	3	4
3. It is hard for me to do sports activity or exercise	0	1	2	3	4
4. It is hard for me to lift something heavy	0	1	2	3	4
5. It is hard for me to take a bath or shower by myself	0	1	2	3	4
6. It is hard for me to do chores around the house	0	1	2	3	4
7. I hurt or ache	0	1	2	3	4
8. I have low energy	0	1	2	3	4

- Emotional

ABOUT MY FEELINGS (PROBLEMS WITH...)	Never	Almost Never	Some-times	Often	Almost Always
1. I feel afraid or scared	0	1	2	3	4
2. I feel sad or blue	0	1	2	3	4
3. I feel angry	0	1	2	3	4
4. I have trouble sleeping	0	1	2	3	4
5. I worry about what will happen to me	0	1	2	3	4

GOVERNMENT RELATIONS AND COMMUNITY BENEFITS

# PEDSQL SURVEY DOMAINS – CONT.

- Social

HOW I GET ALONG WITH OTHERS (PROBLEMS WITH...)	Never	Almost Never	Sometimes	Often	Almost Always
1. I have trouble getting along with other teens	0	1	2	3	4
2. Other teens do not want to be my friend	0	1	2	3	4
3. Other teens tease me	0	1	2	3	4
4. I cannot do things that other teens my age can do	0	1	2	3	4
5. It is hard to keep up with my peers	0	1	2	3	4

- School

ABOUT SCHOOL (PROBLEMS WITH...)	Never	Almost Never	Sometimes	Often	Almost Always
1. It is hard to pay attention in class	0	1	2	3	4
2. I forget things	0	1	2	3	4
3. I have trouble keeping up with my schoolwork	0	1	2	3	4
4. I miss school because of not feeling well	0	1	2	3	4
5. I miss school to go to the doctor or hospital	0	1	2	3	4

# RHEUMATOLOGY HHSC-APPROVED PATIENT SUBSET

- Diagnoses: Lupus, bleeding disorders, vasculitis, scleroderma, polymyositis, or severe complications of rheumatoid arthritis and patients who are on continuous injectable medications.
- Age: 2-18 years

# PEDSQL FOLLOW UP SURVEY PROCESS

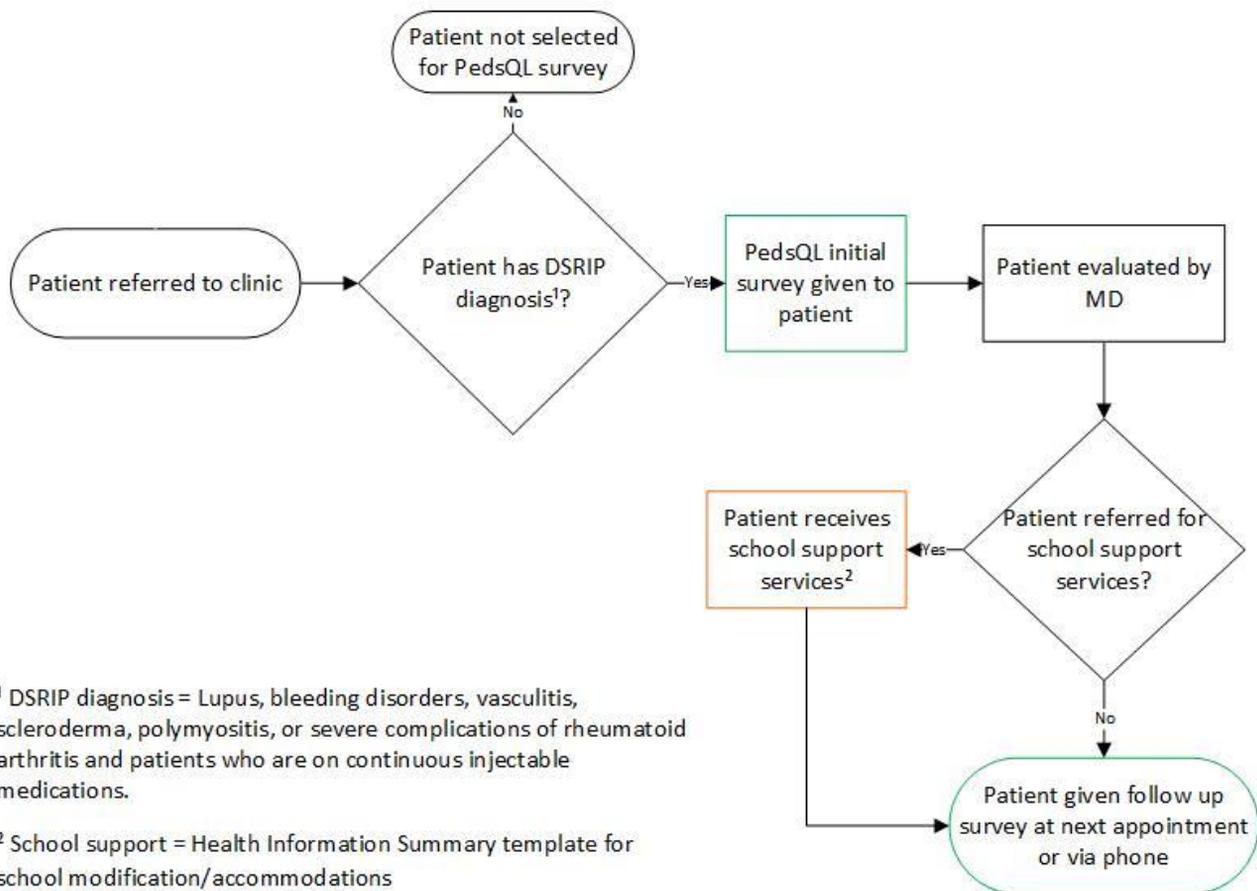
- Timeframe
  - 3-6 months after initial survey
  - Again at 9-12 months on case by case basis
- Patient can be surveyed in person or over the phone
  - In person survey can be done in any clinic, regardless of where initial survey was completed
- Physician champions are notified of low scores (low score= $<50$ ).
  - If child/parent report lower average QOL scores at follow up than they did initially, patient is flagged in database for additional follow up survey a few months later.

# PRELIMINARY PEDSQL DATA

- Initial Surveys (DY4/Baseline: Oct. 1, 2014-Sept. 30, 2015)
  - 65 patients surveyed
  - Total Average Score: 72.57
- Demonstration Year 5 (Oct. 1, 2015-Sept. 30, 2016)
  - Follow Up Surveys to-date: 63 patients
    - Total Average Score: 79.64
    - DY5 Goal (To be achieved by Sept. 30, 2016): 82.57
  - Initial DY5 Surveys to-date: 40 patients
    - Total Average Score: 66.99

# Rheumatology PedsQL Process Map

As of 11/23/15



<sup>1</sup> DSRIP diagnosis = Lupus, bleeding disorders, vasculitis, scleroderma, polymyositis, or severe complications of rheumatoid arthritis and patients who are on continuous injectable medications.

<sup>2</sup> School support = Health Information Summary template for school modification/accommodations

# RHEUMATOLOGY DSRIP PDSA CYCLE #1

PDSA cycle #	Start Date:	End Date:	Measure PEDSQL Score	Intervention School Liaison
1				
Plan	<p>Improve PEDSQL score with intervention of School Support</p> <p>Prediction: What did you expect to happen?</p> <p>Increase in school support and partnership in the care of our patients.</p> <p>Plan: What questions will be answered (Who, What, When, Where)? We hope to have our provider, the patient and the school in alignment with the needs for the patient's care through specific communication around the patient's social needs at school.</p> <p>What data will be collected (Who, What, When, Where)? PEDsQL score in clinic and at follow up visits</p>			
Do	<p>The provider team will implement school modification for each patient and work with our team to assure the patient is aware of the plan and that communication is presented to the patient's school.</p> <p>Document observations &amp; Record data.</p> <p>EPIC report on school modification letters</p>			
Study	<p>Quality of life score before and after school modification letter is added.</p> <p>Compare prediction to results of PDSA cycle.</p> <p>Not yet able to observe an improvement in the PEDsQL score</p> <p>Summarize what was learned (challenges, accomplishments, unintended consequences).</p> <p>Patient, Family and School is more aware of the patient's needs at school.</p>			
Act	<p>Using physician extenders to assure the School Modifications are in for identified patients</p> <p>Should the team implement the findings from this PDSA cycle?</p> <p>EPIC Data is retrieve and will analyze data to present to our team</p> <p>Is the team ready to make a change?</p> <p>Yes, Discussions at bi-monthly Patient Care Multidisciplinary rounds</p> <p>Consider next PDSA cycle—what additional cycles need to be run? Review of data for next steps.</p>			

# RHEUMATOLOGY DSRIP PDSA CYCLE #2

PDSA cycle #	Start Date:	End Date:	Measure	Intervention
2	7.12.2016		PEDSQL Score	Follow Up Phone Calls
Plan	<p>Objective for cycle: Improve PEDSQL follow up score with intervention of Clinic Phone calls to patients</p> <p>Prediction: Contact from clinic will improve patient reported HR-QOL as concerns can be addressed sooner than having to wait to come in for an appointment</p> <p>Plan: Clinic staff will contact patient and their parent to discuss patient HRQOL concerns one week prior to follow up survey appointment. Staff will also contact those patients and/or parents who have reported lower follow up scores than initial scores to determine if additional support or referrals can be given by clinic to help with HR-QOL.</p> <p>What data will be collected? PEDsQL score will be collected at follow up in clinic, and at subsequent follow up encounters as needed, by QOL Coordinators. Phone calls with patients will be tracked via EPIC by clinic staff.</p>			
Do				
Study				
Act				

# PATIENT INTERVENTIONS

- School and Social Support Programs
  - Children with Rheumatologic conditions experience time away from school due to medication regimes & chronic condition.
  - School modification/accommodation (504) form available for use in EPIC
  - Universal medication administration form for patients needing to take prescription medications in school is in the works.

# LESSONS LEARNED

- The importance of mental and psychological wellbeing, and how this overall affects the other aspect of the child/adolescent health, is more apparent when viewing trend of PedsQL scores.
  - Demonstrates evidence of great need for mental health provision (e.g. psychologist) and should be part of a protocol care for chronic illnesses, especially among patients with juvenile lupus and lupus spectrum.
  - Psychology care has been the most difficult and only scantily provided, mainly because of lack /absence of access.
- What's worked well for us?
  - The school modification form (SMF) is part of the EMR and can be updated as the patient's condition warrants.
  - SMF has provided more clarity for the schools around specific accommodation recommendations for each patient.
  - Communication with the school representatives have improved.
  - Patients feel empowered to have discussions with their child's school for the accommodations when they have the SMF as a reference.
- Continue to work at ...
  - Increasing use of SMF in our group and other TCH specialties.
  - Gaining acceptance of SMF in different educational facilities.



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**COMMENTS/QUESTIONS?**