

# Parent Reported Outcomes in Young Children With Disorders/ Differences of Sex Development

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## Introduction

- There is paucity of information of health-related quality of life outcomes in parents and young children with Disorders/ Differences of Sex Development (DSD).
- There are a lack of parent reported outcome measures (PRO) that can be routinely assessed in a busy outpatient setting.

## Aims

- Develop PRO questionnaires for children <7 years.
- Explore feasibility of integrating questionnaires into routine clinic setting.
- Determine whether the psychosocial impact on parents of a child with DSD is different to that of other endocrine conditions.

## Methods

### Questionnaires

#### Parent Reported Outcome Measures (PROs)

#### Parent Self-Report (PSR) 0 - <7y

#### Parent Proxy-Report (PPR) 2 - 6y

#### Assessment of parental experiences

#### Parental report of child's experiences

- Healthcare Communication
- Talking to others
- Experiences (Stigma)
- Future concerns
- Medications
- Clinic visits
- Surgery
- Mood

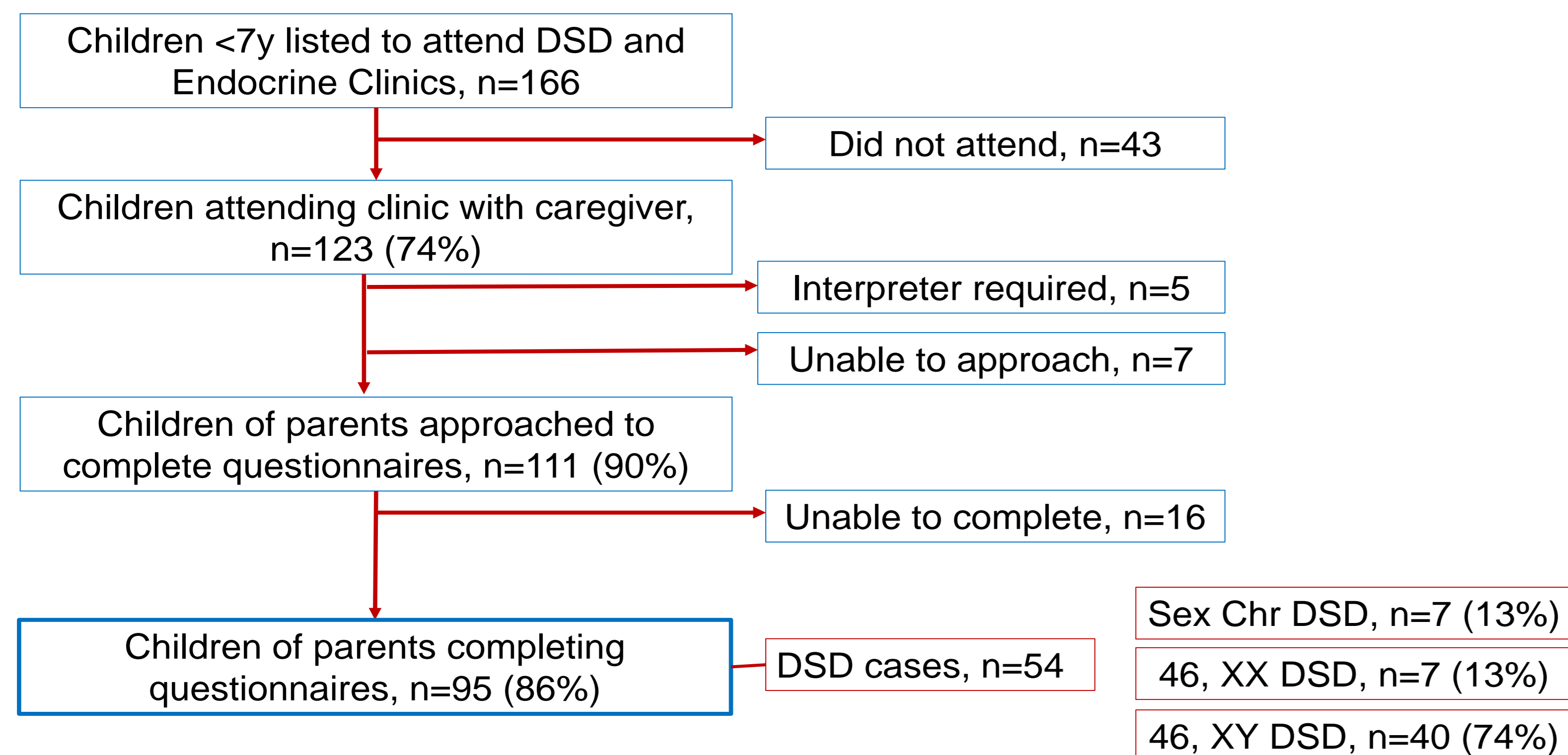
- Anxiety
- Depression
- Anger
- Peer relationships
- Experiences (Stigma)
- Clinic visits
- Medication
- Missed School Days

### Questionnaire domains and scoring

Questionnaire Domains	Items	Derived from:	High subscale scores indicate:	Sample mean (SD) from reference data		
				Mothers	Fathers	Sample- All
<b>Parent Self-Report</b>						
Communication	2	QOL-DSD	Better outcome	74.86 (16.93)	69.97 (23.15)	-
Talking to Others	5	QOL-DSD	Better outcome	64.03 (24.52)	85.55 (16.80)	-
Future Concerns	7	QOL-DSD	Better outcome	55.37 (25.86)	79.14 (13.71)	-
Medication	4	QOL-DSD	Better outcome	70.39 (28.20)	49.10 (28.31)	-
Clinic Visit	4	QOL-DSD	Better outcome	72.08 (27.81)	33.38 (25.80)	-
Surgery	4	QOL-DSD	Better outcome	38.03 (25.12)	81.10 (24.51)	-
Stigma	10	Experiences & reactions- Parent	Poorer outcome	1.76 (0.63)	1.56 (0.44)	-
<b>Mood</b>						
Mood	4	PHQ-4	Poorer outcome	-	-	2.5 (2.8)
<b>Parent Proxy-Report</b>						
Anxiety	4	PROMIS	Poorer outcome	-	-	50 (10)
Depression	4	PROMIS	Poorer outcome	-	-	50 (10)
Anger	5	PROMIS	Poorer outcome	-	-	50 (10)
Peer Relations	4	PROMIS	Better outcome	-	-	50 (10)
Stigma	4	Experiences & reactions- Child	Poorer outcome	2.28 (0.91)	2.05 (0.81)	-
<b>Clinic Visit &amp; Medication</b>						
Clinic Visit & Medication	7	QOL-DSD	Better outcome	64.98 (24.49)	78.10 (22.56)	-

## Results

### Case recruitment



## Results

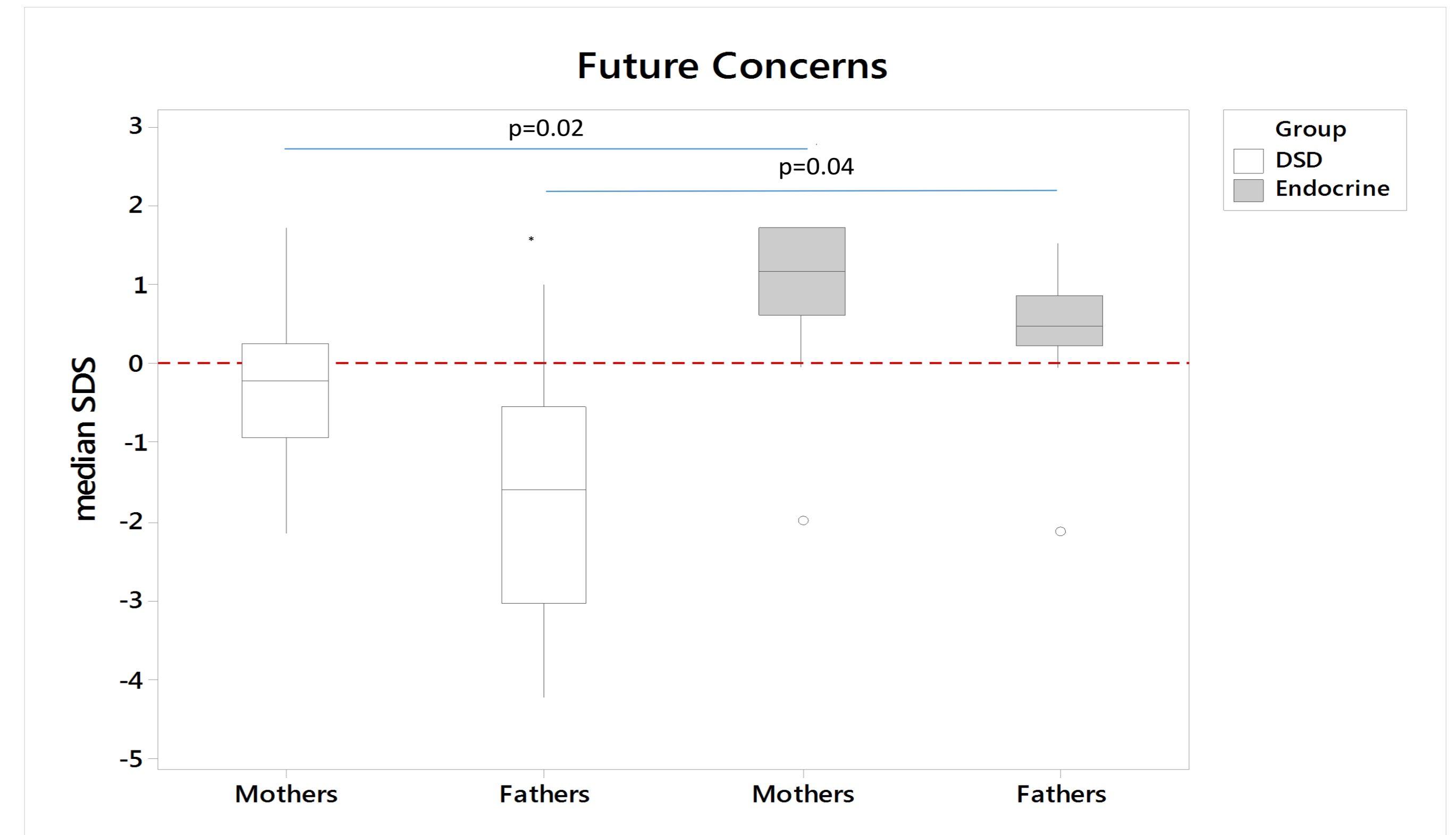
- 100% parent acceptability reported.
- Less than 10 minutes to complete.

### PSR questionnaire

- Fathers of children with DSD had less stress associated with Clinic Visits (p=0.02) and managing their child's Medication (p=0.04).

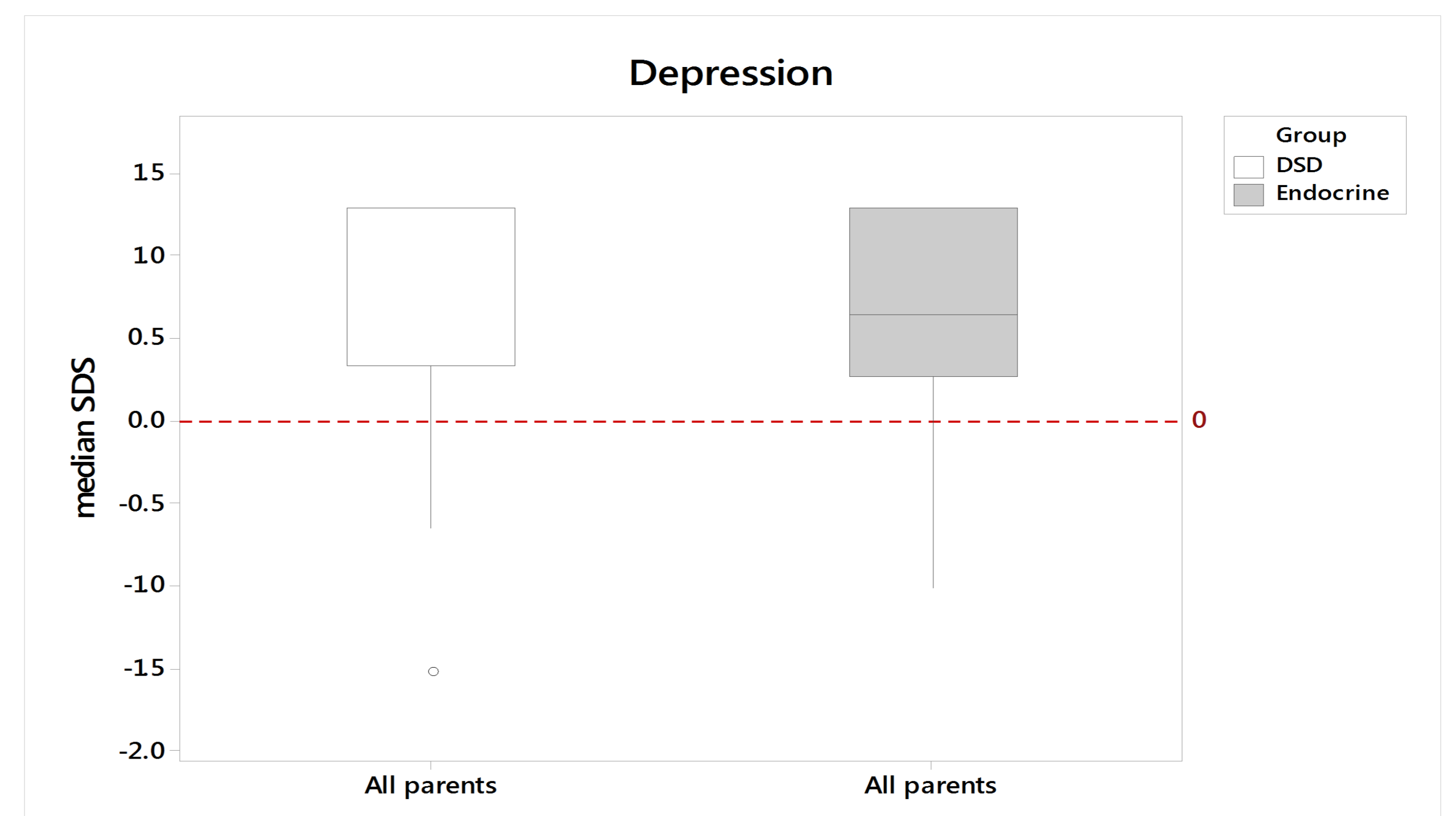


- Parents of children with DSD reported greater Future Concerns in relation to their child's condition than parents of children with other Endocrine conditions (p<0.05).



### PPR questionnaire

- Parents of children with DSD and other Endocrine conditions reported less Depressive symptoms compared to reference data (p<0.05).



## Conclusions

- The use of PRO tools in parents and young children with DSD is an acceptable practice.
- PRO tools can be routinely used in the outpatient setting to assess and monitor parent and patient needs.
- DSD was associated with greater parental concerns over a child's future than other Endocrine conditions
  - Opportunities for targeted intervention