

Background

Despite advances in genetic diagnosis and surgical technique, and guidance from the Consensus Statement on Intersex Disorders, aspects of clinical management in disorders/differences of sex development (DSD) remain unsettled

Actively debated decision points include:

- Gender of rearing in specific syndromes
- Genital surgery prior to the patient developing the capacity to provide assent
- Uncertainty over how and when to best educate young patients about diagnostic and medical management history details

Objective

- Survey expert opinion & treatment recommendations on clinical management of children born with varying DSD at 2 points in time: before and after the Consensus Statement
- Examine how physician characteristics and time (pre vs post consensus) predict recommendations

Methods

Web-based Survey

5 Case vignettes:

- XX "Mild" CAH
- XX "Severe" CAH
- Microphallus
- partial AIS
- Penile Amputation

Asked for recommendations about:

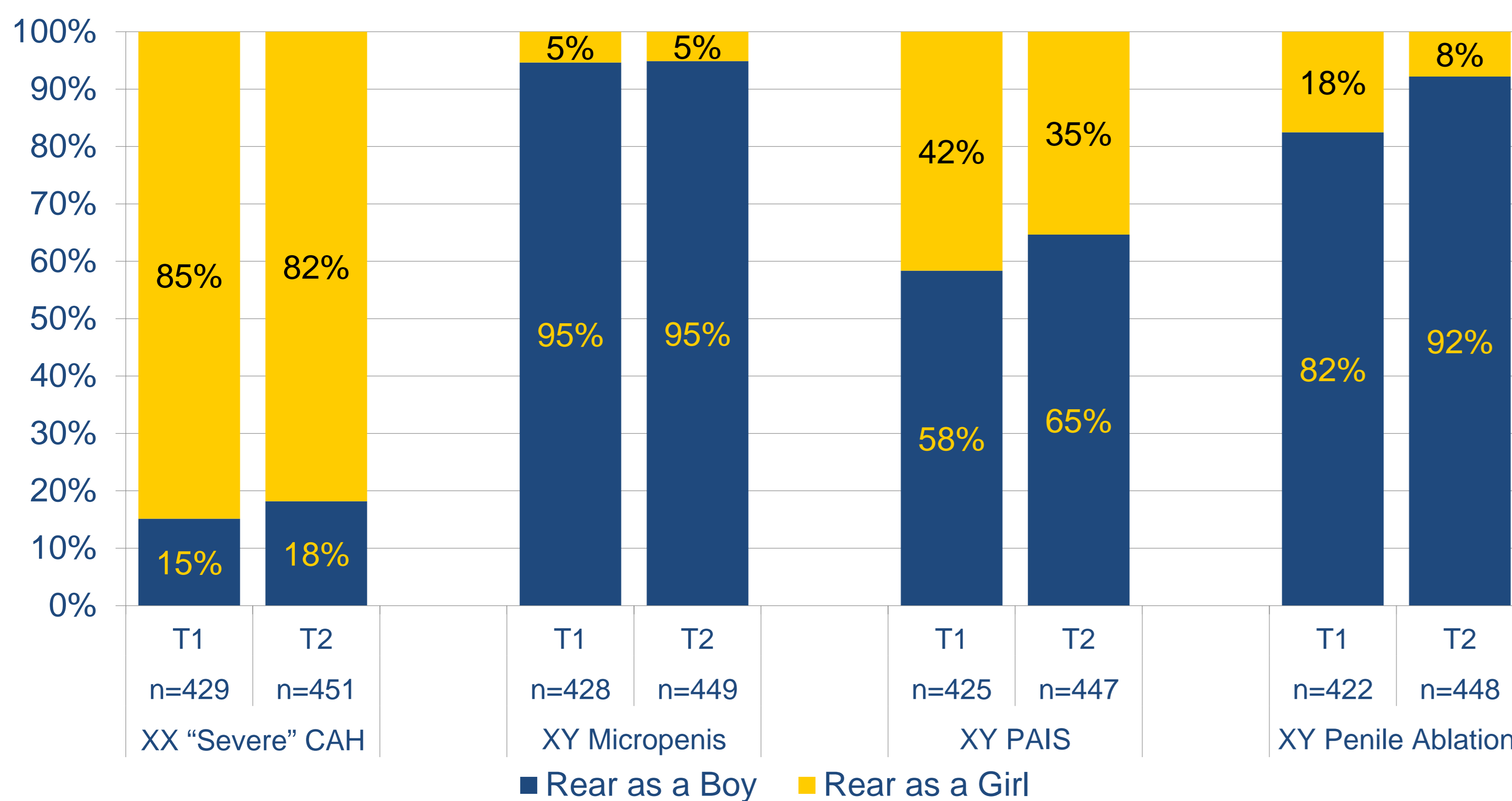
- Gender of rearing
- Surgical decision-making, including timing
- Age for educating pediatric patients about their own diagnostic and medical/surgical management history

Physician characteristics	2003-2004 (T1)			2010-2011 (T2)		
	n	%	participation rate %	n	%	participation rate %
Specialty						
Endocrinology	300	69.4	56.3	337	74.1	42.6
Urology	132	30.6	57.4	118	25.9	54.6
Gender						
Men	307	71.1		280	61.5	
Women	125	28.9		175	38.5	
Practice setting						
Medical school / hospital	288	73.3		335	73.6	
Other	105	26.7		120	26.4	
		median	range	median	range	
Physician age (years)		52	33 – 83	52	34 – 86	
DSD cases seen in career		50	3 – 1000	45	2 – 2000	

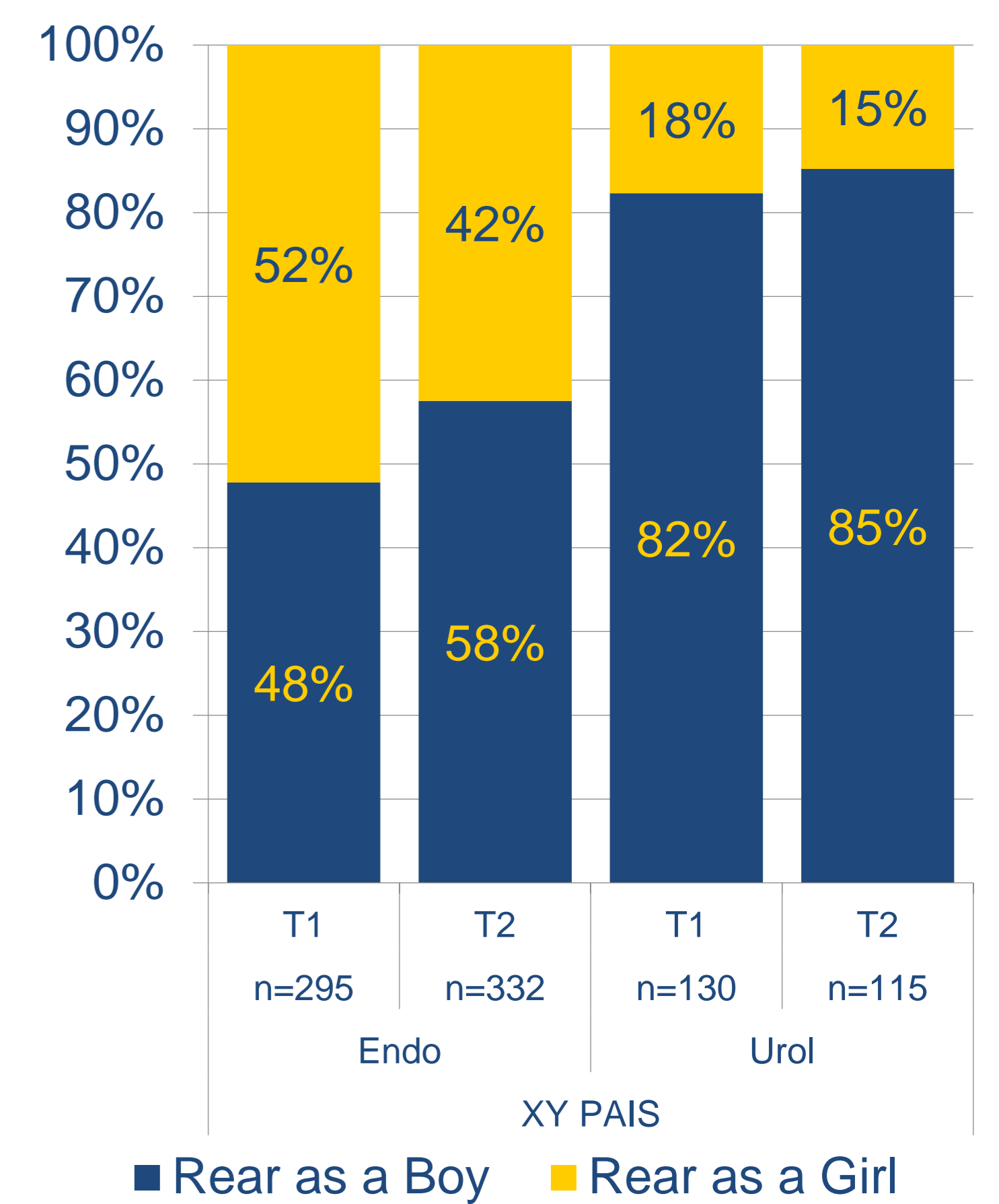
T1 & T2 Subsample: 137 endocrinologists and 72 urologists

Results & Conclusions

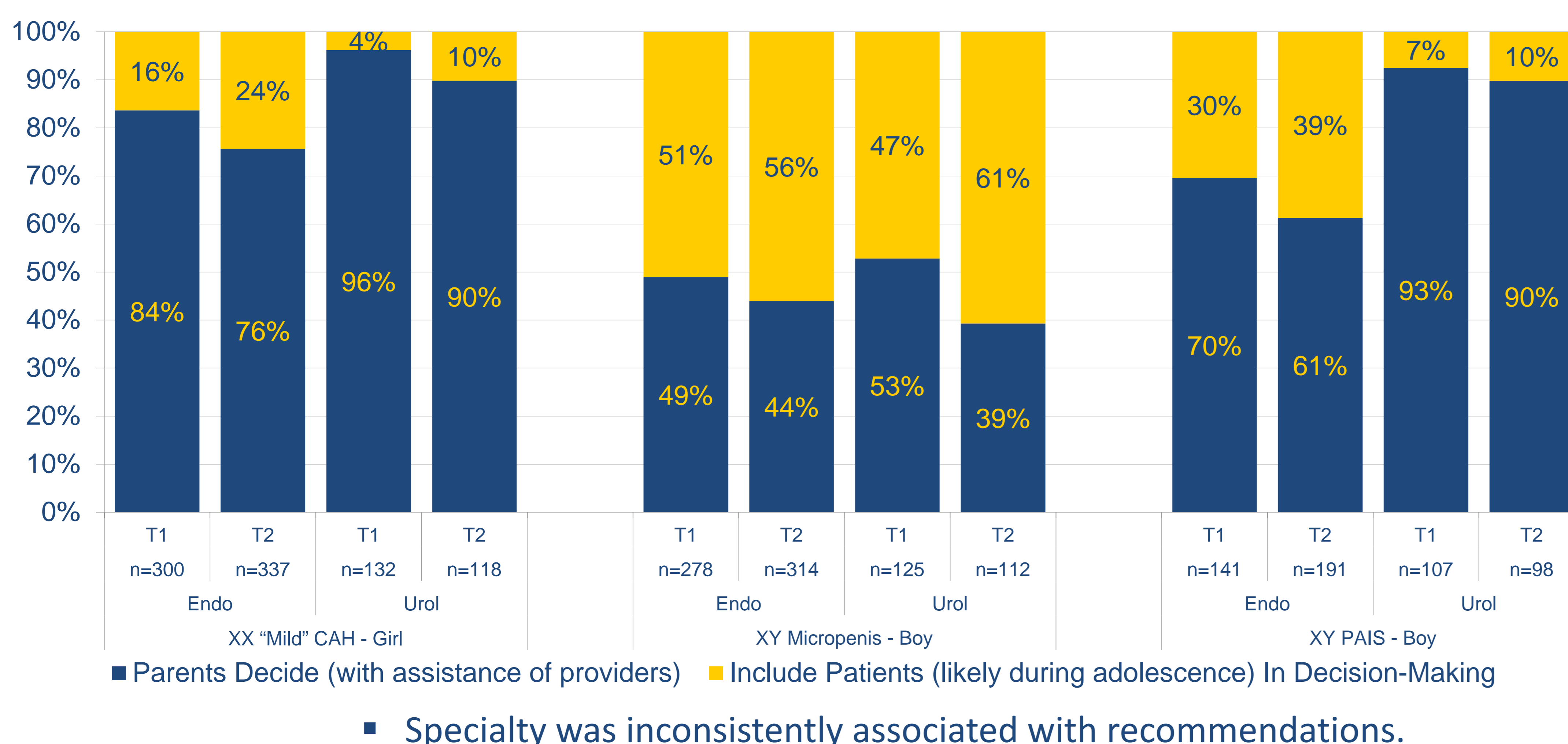
Gender of Rearing Recommendations: Pre- vs Post Consensus



- Variability existed in gender of rearing recommendations
- Similar variability was observed for surgical and disclosure decisions (not shown here)
- Differences by physician characteristics emerged, but did not form a systematic pattern across vignettes



Surgical Decision-Making: Endocrinology vs Urology



- Specialty was inconsistently associated with recommendations.

Discussion

- Variability in clinical management recommendations, independent of case characteristics, is a cause for concern
 - particularly for parents faced with contrasting recommendations
- There is an acute need to account for variability in provider recommendations which may be untethered to evidence