

## **Supplementary Material**

### **Supplementary Methods**

#### *Survey Design and Sample Size*

The study was designed as a cross-sectional assessment. The study was reviewed by the Texas Tech University Health Sciences Center Institutional Review Board and was exempt from requiring participant consent due to the anonymity of the survey answers. The survey questions were developed and reviewed by a team of pediatric nephrologists. The questions were grounded on a thorough literature review of qualitative and quantitative studies of adolescent females and women's health topics. The survey was first discussed and tested within a small group of expert nephrologists that care for adolescent females and young adult females. In 2018, the survey was presented to a larger group at a Pediatric Nephrology Research Consortium (PNRC) meeting. The survey was distributed electronically from April to September 2019 using Qualtrics Online Survey Platform to all 305 adult nephrologists and pediatric nephrologists (from 88 participating centers in the U.S. and Canada) who were members of the PNRC. Reminder emails were sent monthly. Survey submissions were voluntary and anonymous. The survey included a total of 19 questions (Supplementary Figure 1). The first questions addressed provider characteristics, including: demographics (age and gender); years in practice as a nephrologist; practice location (response options in Table 1); prior formal training in obstetric nephrology and/or women's health. Providers were then asked to report how frequently they documented adolescents' ages at menarche, menstrual cycle history and patterns, contraceptive use, sexual activity, history of sexually transmitted disease, discussions about fetotoxicity or infertility risks associated with specific medications, and discussions about family planning. These responses were rated using a Likert

scale, on a spectrum of “Never” to “Always”. Finally, provider confidence managing reproductive health and pregnancy-related issues in adolescent females with CKD/ESRD were assessed using a Likert Scale, on a spectrum of “Not at all” to “Very Confident”.

### *Data Analysis*

All survey responses were summarized and analyzed using descriptive statistics (percentages or frequencies) via the Qualtrics Data Analysis Platform (<https://www.qualtrics.com/>).

### *Survey*

This survey is for Nephrologists who take care of adolescents (12-18 years of age). The purpose of this survey is to gain a better understanding of the reproductive care provided to teenage patients by Nephrology providers in day-to-day practice. You are requested to take this survey because you are a nephrology provider. Please answer to the best of your ability.

#### **Part A: Provider information**

Age \_\_\_\_\_

Sex (please circle) Male Female Prefer not to answer

Country of nephrology practice: \_\_\_\_\_

How many years have you been in practice: \_\_\_\_\_

In what Country did you complete your Nephrology training? \_\_\_\_\_

Current practice setting:

- Community
- Academic/University
- Hybrid
- Still in training
- Other

What is the clinical scope of your practice? (Check all that apply)

- Pediatric nephrology
- Adult nephrology

What percent of your job is dedicated to the clinical care of patients?

- 0-24%
- 25-49%
- 50-74%

- 75-100%

What percentage of your patients are adolescents?

- 0-24%
- 25-49%
- 50-74%
- 75-100%

Did your nephrology training include any formal training in

- Obstetric nephrology
- Women's health

**Part B: Clinical Survey**

At what age do you start doing Tanner staging (years)? \_\_\_\_\_  
 How often do you do Tanner staging?

- never
- yearly
- every 6 months
- every visit
- intermittently/no set schedule
- only when required for research study

Please tell us how frequently you **asses and document** in the chart the following when evaluating an adolescent female in clinic?

	Never	Rarely	Sometimes	Often	Always
1. Age of first menstrual cycle					
2. Pregnancy history					
3. History of pregnancy termination/loss					
4. LMP Date					
5. Prior conception use					
6. Prior consensual or nonconsensual sexual Activity					

7. Sexual Partner Preference (male/female/both)					
8. Number of Sexual Partners					
9. STD/STIs					
10. Documentation of a discussion on the risk of fetotoxicity with ACEi/ARBS or mycophenolate use					
11. Document a negative pregnancy test before starting a fetotoxic medication					
12. Discuss the risk of infertility with cyclophosphamide					
13. Discuss fertility-preserving options (hormonal ovarian suppression, oocyte cryopreservation) with exposure to cyclophosphamide					
14. Discussion on patient's desire for future pregnancy					

Please indicate your **level of confidence** in your ability to care for adolescents with CKD/ESRD in the following situations.

	A) Not at all	B) Somewhat confident	C) Confident	D) Very confident
1. Manage menstrual disorders				
2. Determining need for fertility preservation				
3. Assess bone health				

4. Counsel on fetal outcomes by CKD stage				
5. Counsel on fetotoxicity related to immunosuppression				
6. Discuss the risks and benefits of contraception				

Please indicate your **level of confidence** in your ability to counsel an adolescent on the following contraception options.

	A) Not at all	B) Somewhat confident	C) Confident	D) Very confident
1. Oral contraceptive pills				
2. Injectable Hormonal Contraception				
3. IUD				
4. Contraceptive Implants				
5. Vaginal Ring				
6. Skin Patch				
7. Barrier Devices				
8. Contraceptive foam/jelly/inserts/sponges				

On average, how many adolescents of childbearing age with kidney disease have you counseled on contraception in the last 12 months?

- 0
- Less than one per month
- 1-2 per month
- 3-4 per month
- 5 or more per month

Who prescribes contraception for your adolescent patients? (Check all that apply)

- I do
- Adolescent medicine
- Gynecology
- Pediatrician/primary care physician
- Other

On average, how many pregnant adolescents have you cared for in the last 12 months?

- a. 0

- b. 1-2
- c. 3-4
- d. 5 or more

Who takes care of pregnant adolescents in your practice?

- I refer to adult nephrology
- I keep them and manage them myself
- I co-manage with an obstetrics doctor
- Other

If one of your patients gets pregnant, and you refer them to adult nephrology, when will they return to your pediatric-focused practice?

- Never – they continue to follow with adult nephrology
- Post-delivery once cleared by OB
- Other

### Supplementary References

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## Study Limitations

While this study provides valuable information on the frequency of documenting and/or discussing women's health issues, and level of confidence in managing women's health problems of nephrologists caring for adolescent female patients with CKD, it has several limitations. . Firstly, this study only shows the reported activities of providers, which does not necessarily reflect the actual practice of providers in these settings. Furthermore, asking providers to describe prior

practices might have resulted in recall bias. Moreover, provider personal beliefs and the era of their medical education may also result in potential biases in how they deliver reproductive care to adolescents.

Also, although responses were anonymous, we cannot exclude the possibility of either inaccurate or untrue responses. Nevertheless, the overall sub-optimal practices reported by these providers suggest that the providers likely did not falsify their responses to avoid critique. We also did not specifically ask how many female adolescents the providers care for each year, rather the proportion of adolescents that make up their practice. Accordingly, patient numbers might have been very small for some of the providers. Since a majority of the providers were members of an academic consortium, and most practiced in an academic setting, practices reported in this study additionally might not reflect practices occurring in community or rural settings. Finally, we did not examine potential solutions to the barriers in knowledge, confidence, and competence identified in this study, but we hope to do this as a focus of future work that could include an educational symposium and/or a future publication on this important topic.

### **Abbreviations**

AAP	American Academy of Pediatrics
CKD	Chronic Kidney Disease
IUD	Intrauterine Device
LARC	Long-Acting Reversible Contraceptive
LMP	Last Menstrual Period
STI	Sexually Transmitted Infection

### **Disclosures**



Dr. Almaani consults with Aurinia Pharmaceuticals, outside the submitted work. All other authors declare no conflicts of interests or competing interests

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