Appendix 1: Survey Text

Ougstion	Decrease			
Question	Response			
1. Have you ever enrolled a patient in a randomized controlled trial?	Yes/no			
	Abusis/mara willing/unchanged/lass			
2. Would you recommend to your patients	Always/more willing/unchanged/less			
to participate in a randomized controlled trial if:	willing/never			
triai ii.				
Patients either receive only a standard				
therapy or a novel therapy				
3. Would you recommend to your patients	Always/more willing/unchanged/less			
to participate in a randomized controlled	willing/never			
trial if:	willing/liever			
triai ii.				
The adverse effects are different in different				
arms of the study.				
4. Would you recommend to your patients	Always/more willing/unchanged/less			
to participate in a randomized controlled	willing/never			
trial if:	willing/liever			
triai ii.				
The study was multi-center				
5. Would you recommend to your patients	Always/more willing/unchanged/less			
to participate in a randomized controlled	willing/never			
trial if:	<b>3</b> ,			
The study was single-center				
6. Would you recommend to your patients	Always/more willing/unchanged/less			
to participate in a randomized controlled	willing/never			
trial if:				
The patient has a severe illness				
7. Would you recommend to your patients	Always/more willing/unchanged/less			
to participate in a randomized controlled	willing/never			
trial if:				
The patient has a mild illness				
8. Would you recommend to your patients	Always/more willing/unchanged/less			
to participate in a randomized controlled	willing/never			
trial if:				
The nations has a near progression				
The patient has a poor prognosis	Always/more willing/washenged/less			
9. Would you recommend to your patients	Always/more willing/unchanged/less			
to participate in a randomized controlled	willing/never			

trial if:	
The patient has a good prognosis	
10. Would you recommend to your patients	Always/more willing/unchanged/less
to participate in a randomized controlled	willing/never
trial if:	G,
The study will require additional blood	
draws	
11. Would you recommend to your patients	Always/more willing/unchanged/less
to participate in a randomized controlled	willing/never
trial if:	
The study will require additional clinic visits	
12. Would you recommend to your patients	Always/more willing/unchanged/less
to participate in a randomized controlled	willing/never
trial if:	
Patients are given a financial incentive to	
participate	Al a description of a share and the same
13. Would you recommend to your patients to participate in a randomized controlled	Always/more willing/unchanged/less willing/never
trial if:	wiiiiig/fievei
Parents are given a financial incentive to	
participate	
14. Would you recommend to your patients	Always/more willing/unchanged/less
to participate in a randomized controlled trial if:	willing/never
triai ii.	
Providers are given a financial incentive to	
enroll patients	
15. Please indicate your agreement with the	Strongly
following statements about randomized	agree/agree/unsure/disagree/strongly
controlled trials:	disagree
I fool that anyalling nations in wardows in a	
I feel that enrolling patients in randomized controlled trials improves the quality of their	
care.	
16. Please indicate your agreement with the	Strongly
following statements about randomized	agree/agree/unsure/disagree/strongly
controlled trials:	disagree

	1
I feel that enrolling patients in randomized controlled trials makes them feel like "guinea pigs."	
17. Please indicate your agreement with the	Strongly
following statements about randomized	agree/agree/unsure/disagree/strongly
controlled trials:	disagree
	4.545. 66
I feel that enrolling patients in randomized	
controlled trials may negatively affect the	
doctor-patient relationship.	
18. Please indicate your agreement with the	Strongly
following statements about randomized	agree/agree/unsure/disagree/strongly
controlled trials:	disagree
Controlled trials.	uisagi ee
I feel that enrolling patients in randomized	
controlled trials may restrict my	
management of them.	
19. Please indicate your agreement with the	Strongly
following statements about randomized	agree/agree/unsure/disagree/strongly
controlled trials:	disagree
I feel that randomized controlled trials allow	
my patients to receive the best new therapy.	
20. Please indicate your agreement with the	Strongly
following statements about randomized	agree/agree/unsure/disagree/strongly
controlled trials:	disagree
Controlled trials.	uisagi ee
I feel that I have adequate institutional	
resources to recommend to my patients	
enrollment in randomized control trials.	
21. What percentage of your professional	0%/1-30%/31-69%/>70%
effort is devoted to clinical research	
22. What best describes your principal area	Academic Center/Private Practice
of practice	
23. How many years have passed since	<5/5-15/>15
completion of your fellowship	

Appendix: Survey responses

## Pediatric Nephrologist Beliefs About Randomized Controlled Trials (N=130)

Question	Response %				
Would you recommend to your patients	<u> </u>				never
to participate in a randomized controlled		willin		willing	
trial if:		g			
The adverse effects are different in	7	19	45	27	2
different arms of the study.					
The study was multi-center	31	40	28	1	0
The study was single-center	15	9	52	24	0
The patient has a severe illness	12	42	34	11	1
The patient has a mild illness	9	22	51	18	0
The patient has a poor prognosis	14	46	31	8	1
The patient has a good prognosis	10	13	54	22	0
The study will require additional blood	10	10	61	19	0
draws					
The study will require additional clinic	11	11	60	18	0
visits					
Patients are given a financial incentive	10	29	56	4	1
to participate					
Parents are given a financial incentive	9	25	54	10	2
to participate					
Providers are given a financial	4	11	53	21	11
incentive to enroll patients					
Please indicate your agreement with the	Strongl	Agree	Unsure	Disagree	Strongly
following statements about randomized	y agree				Disagree
controlled trials:					
I feel that enrolling patients in	30	41	21	7	1
randomized controlled trials improves					
the quality of their care.					
I feel that enrolling patients in	0	10	10	59	21
randomized controlled trials makes					
them feel like "guinea pigs."					
I feel that enrolling patients in	0	3	7	63	27
randomized controlled trials may					
negatively affect the doctor-patient					
relationship.					_
I feel that enrolling patients in	2	38	11	44	5
randomized controlled trials may					
restrict my management of them.	11	42	24	1.0	
I feel that randomized controlled trials	11	42	31	16	0
allow my patients to receive the best					
new therapy.					

I feel that I have adequate institutional	14	34	20	24	8
resources to recommend to my					
patients enrollment in randomized					
control trials.					

- 1. Peto R, Collins R, Gray R 1995 Large-scale randomized evidence: large, simple trials and overviews of trials. J Clin Epidemiol 48:23-40.
- 2. Eden T 2000 Evidence based medicine. Arch Dis Child 82:275-277.
- 3. Barton S 2000 Which clinical studies provide the best evidence? The best RCT still trumps the best observational study. BMJ 321:255-256.
- 4. Chessells JM 1992 Treatment of childhood acute lymphoblastic leukaemia: present issues and future prospects. Blood Rev 6:193-203.
- 5. Strippoli GF, Craig JC, Schena FP 2004 The number, quality, and coverage of randomized controlled trials in nephrology. J Am Soc Nephrol 15:411-419.
- 6. Cohen E, Goldman RD, Ragone A, Uleryk E, Atenafu EG, Siddiqui U, Mahmoud N, Parkin PC 2010 Child vs adult randomized controlled trials in specialist journals: a citation analysis of trends, 1985-2005. Arch Pediatr Adolesc Med 164:283-288.
- 7. Aripin KN, Choonara I, Sammons HM 2010 A systematic review of paediatric randomised controlled drug trials published in 2007. Arch Dis Child 95:469-473.
- 8. Campbell H, Surry SA, Royle EM 1998 A review of randomised controlled trials published in Archives of Disease in Childhood from 1982-96. Arch Dis Child 79:192-197.
- 9. Gipson DS, Trachtman H, Kaskel FJ, Greene TH, Radeva MK, Gassman JJ, Moxey-Mims MM, Hogg RJ, Watkins SL, Fine RN, Hogan SL, Middleton JP, Vehaskari VM, Flynn PA, Powell LM, Vento SM, McMahan JL, Siegel N, D'Agati VD, Friedman AL 2011 Clinical trial of focal segmental glomerulosclerosis in children and young adults. Kidney Int 80:868-878.
- 10. Shaddy RE, Denne SC 2010 Clinical report--guidelines for the ethical conduct of studies to evaluate drugs in pediatric populations. Pediatrics 125:850-860.
- 11. Starko KM, Ray CG, Dominguez LB, Stromberg WL, Woodall DF 1980 Reye's syndrome and salicylate use. Pediatrics 66:859-864.
- 12. Mello HS 1967 The mechanism of tetracycline staining in primary and permanent teeth. J Dent Child 34:478-487.
- 13. Craft AW, Brocklebank JT, Hey EN, Jackson RH 1974 The 'grey toddler'. Chloramphenicol toxicity. Arch Dis Child 49:235-237.
- 14. Amiel P, Moreau D, Vincent-Genod C, Alberti C, Hankard R, Ravaud P, Gottot S, Gaultier C 2007 Noninvitation of eligible individuals to participate in pediatric studies: a qualitative study. Arch Pediatr Adolesc Med 161:446-450.
- 15. Walterspiel JN 1990 Informed consent: influence on patient selection among critically ill premature infants. Pediatrics 85:119-121.
- 16. Caldwell PH, Butow PN, Craig JC 2002 Pediatricians' attitudes toward randomized controlled trials involving children. J Pediatr 141:798-803.
- 17. Taylor KM, Feldstein ML, Skeel RT, Pandya KJ, Ng P, Carbone PP 1994 Fundamental dilemmas of the randomized clinical trial process: results of a survey of the 1,737 Eastern Cooperative Oncology Group investigators. J Clin Oncol 12:1796-1805.

- 18. Siminoff LA, Zhang A, Colabianchi N, Sturm CM, Shen Q 2000 Factors that predict the referral of breast cancer patients onto clinical trials by their surgeons and medical oncologists. J Clin Oncol 18:1203-1211.
- 19. Benson AB, 3rd, Pregler JP, Bean JA, Rademaker AW, Eshler B, Anderson K 1991 Oncologists' reluctance to accrue patients onto clinical trials: an Illinois Cancer Center study. J Clin Oncol 9:2067-2075.
- 20. Taylor KM 1992 Integrating conflicting professional roles: physician participation in randomized clinical trials. Soc Sci Med 35:217-224.
- 21. Taylor KM, Shapiro M, Soskolne CL, Margolese RG 1987 Physician response to informed consent regulations for randomized clinical trials. Cancer 60:1415-1422.
- 22. Kinney AY, Richards C, Vernon SW, Vogel VG 1998 The effect of physician recommendation on enrollment in the Breast Cancer Chemoprevention Trial. Prev Med 27:713-719.
- 23. Harth SC, Thong YH 1995 Parental perceptions and attitudes about informed consent in clinical research involving children. Soc Sci Med 41:1647-1651.
- 24. Ferris M, Norwood V, Radeva M, Gassman JJ, Al-Uzri A, Askenazi D, Matoo T, Pinsk M, Sharma A, Smoyer W, Stults J, Vyas S, Weiss R, Gipson D, Kaskel F, Friedman A, Moxey-Mims M, Trachtman H 2013 Patient recruitment into a multicenter randomized clinical trial for kidney disease: report of the focal segmental glomerulosclerosis clinical trial (FSGS CT). Clin Transl Sci 6:13-20.
- 25. Sudman S BN 1982 Asking Questions. Jossey-Bass, University of California, p 397.
- 26. R Development Core Team 2010 R: A language and environment for statistical computing. R Foundation for Statistical Computing, Vienna, Austria.
- 27. Deegens JK, Wetzels JF 2011 Immunosuppressive treatment of focal segmental glomerulosclerosis: lessons from a randomized controlled trial. Kidney Int 80:798-801.
- 28. Mason SA, Allmark PJ 2000 Obtaining informed consent to neonatal randomised controlled trials: interviews with parents and clinicians in the Euricon study. Lancet 356:2045-2051.
- 29. Woroniecki RP, Flynn JT 2005 How are hypertensive children evaluated and managed? A survey of North American pediatric nephrologists. Pediatr Nephrol 20:791-797.
- 30. Teh JC, Frieling ML, Sienna JL, Geary DF 2011 Attitudes of caregivers to management of endstage renal disease in infants. Perit Dial Int 31:459-465.