

**Assessing Patient Preferences in Rare Diseases: Direct Preference Elicitation in the  
Rare Chronic Kidney Disease, Immunoglobulin A Nephropathy**

**Assessing Patient Preferences in Rare Diseases: Direct Preference Elicitation in  
Immunoglobulin A Nephropathy**

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**SUPPLEMENTARY MATERIAL – PATIENT CHARACTERISTICS**

	<b>Overall Sample (N=40)</b>	<b>US (N = 25)</b>	<b>China (N = 15)</b>
<b>Gender, N(%)</b>			
Female	27 (67.5)	17 (68.0)	10 (66.7)
Male	13 (32.5)	8 (32.0)	5 (33.3)
<b>Age, years</b>			
Min, Max	20, 63	20, 63	21,62
Median (Q1, Q3)	41.0 (35.0, 47.8)	44 (39.0, 55.0)	35 (29.5, 39.5)
Mean (SD)	41.6 (11.3)	45.2 (10.7)	35.7 (10.1)
<b>Racial Background, N(%)</b>			
White	17 (68.0)	17 (68.0)	NA
Black or African American	3 (12.0)	3 (12.0)	NA
Asian	1 (4.0)	1 (4.0)	NA
Hispanic or Latino	4 (16.0)	4 (16.0)	NA
Native Hawaiian or other Pacific Islander	0 (0.0)	0 (0.0)	NA
American Indian or Alaska Native	0 (0.0)	0 (0.0)	NA
Prefer not to say	0 (0.0)	0 (0.0)	NA
<b>Employment Status, N(%)</b>			
Employed, full-time	29 (72.5)	16 (64.0)	13 (86.7)
Employed, part-time	3 (7.5)	3 (12.0)	0 (0.0)
Self-employed	2 (5.0)	2 (8.0)	0 (0.0)
Voluntary work	1 (2.5)	1 (4.0)	0 (0.0)
Homemaker	1 (2.5)	1 (4.0)	0 (0.0)
Student	2 (5.0)	1 (4.0)	1 (6.7)

## Eliciting Patient Preferences for Treatment for Rare Diseases

	<b>Overall Sample (N=40)</b>	<b>US (N = 25)</b>	<b>China (N = 15)</b>
Unemployed	0 (0.0)	0 (0.0)	0 (0.0)
Retired	3 (7.5)	2 (8.0)	1 (6.7)
On sick leave	0 (0.0)	0 (0.0)	0 (0.0)
Maternity/paternity leave	0 (0.0)	0 (0.0)	0 (0.0)
Not able to work due to disability	0 (0.0)	0 (0.0)	0 (0.0)
<b>Education Level, N(%)</b>			
Elementary/primary school	0 (0.0)	0 (0.0)	0 (0.0)
Middle School	5 (12.5)	2 (8.0)	3 (20.0)
High School	9 (22.5)	4 (16.0)	5 (33.3)
College/University (BA, BSc)	19 (47.5)	12 (48.0)	7 (46.7)
Postgraduate degree (Masters, MD, PhD)	7 (17.5)	7 (28.0)	0 (0.0)
<b>Health Insurance, N(%)</b>			
Employer-provided insurance (US only)	19 (76.0)	19 (76.0)	NA
Self-provided insurance (US only)	6 (24.0)	6 (24.0)	NA
Veterans Affairs/Military healthcare (US only)	0 (0.0)	0 (0.0)	NA
Medicare (US only)	0 (0.0)	0 (0.0)	NA
Medicaid (US only)	0 (0.0)	0 (0.0)	NA
Urban Employee Basic Medical Insurance (UEBMI) (China only)	9 (60.0)	NA	9 (60.0)
Urban Residence Basic Medical Insurance (URBMI) (China only)	6 (40.0)	NA	6 (40.0)
New Rural Cooperative Medical Scheme (NRCMS) (China only)	1 (6.7)	NA	1 (6.7)

## Eliciting Patient Preferences for Treatment for Rare Diseases

	<b>Overall Sample (N=40)</b>	<b>US (N = 25)</b>	<b>China (N = 15)</b>
Military Insurance (China only)	0 (0.0)	NA	0 (0.0)
None (uninsured)	0 (0.0)	0 (0.0)	0 (0.0)
<b>Time since diagnosis, N(%)</b>			
6-12 months	3 (7.5)	1 (4.0)	2 (13.3)
1-2 years ago	8 (20.0)	5 (20.0)	3 (20.0)
2-5 years ago	8 (20.0)	4 (16.0)	4 (26.7)
5-10 years ago	6 (15.0)	4 (16.0)	2 (13.3)
10-20 years ago	11 (27.5)	8 (32.0)	3 (20.0)
20+ years ago	4 (10.0)	3 (12.0)	1 (6.7)
<b>Current treatment, N(%)</b>			
ACEi/ARB	40 (100.0)	25 (100.0)	15 (100.0)
Corticosteroid	6 (15.0)	3 (12.0)	3 (20.0)
Immuno-suppressant	4 (10.0)	3 (12.0)	1 (6.7)
Other IgAN Treatment	10 (25.0)	7 (28.0)	3 (20.0)
<b>Other treatments, N(%)</b>			
Fish oil	18 (45.0)	16 (64.0)	2 (13.3)
Diet control	34 (85.0)	20 (80.0)	14 (93.3)
Tonsillectomy	5 (12.5)	4 (16.0)	1 (6.7)
Others	4 (10.0)	3 (12.0)	1 (6.7)