

The Humanistic Burden of Rare Kidney Diseases: Understanding the Impact of Focal Segmental Glomerulosclerosis (FSGS) and Immunoglobulin A Nephropathy (IgAN) on Patients and Caregivers Study (HONUS): Preliminary Results for IgAN in the United States (US)

Justyna Szklarzewicz¹, Ute Floege², Daniel Gallego³, Keisha Gibson⁴, Kamyar Kalantar-Zadeh⁵, Kelly Helm⁶, Dale Robinson⁷, Bonnie Schneider⁸, Philip Smith⁷, Kjell Tullus⁹, Mark Bensink¹⁰, Bruce Hendry¹⁰, Wenxi Tang¹¹, Mo Zhou¹¹, Zheng-Yi Zhou¹¹

¹University Hospitals of Leicester NHS Trust, Leicester, UK; ²University Hospital of the RWTH Aachen University, Aachen, Germany; ³EKPF European Kidney Patients Federation, FEDERACION ALCER Spanish Kidney Patient Federation, Padova, Italy; ⁴University of North Carolina at Chapel Hill School of Medicine, Chapel Hill, NC, USA;

⁵School of Medicine University of California, Irvine, CA, USA; ⁶NephCure Kidney International, King of Prussia, PA, USA; ⁷Kidney Research UK, Peterborough, UK; ⁸The IGA Nephropathy Foundation of America, Wall, NJ, USA; ⁹Great Ormond Street Hospital, London, UK; ¹⁰Travere Therapeutics, Inc., San Diego, CA, USA;

¹¹Analysis Group, Boston, MA, USA.

To obtain a PDF of this poster:



Scan the QR code OR visit www.travereposters.com

Charges may apply.

No personal information is stored.

- **JS, UF, DG, KG, KK-Z, KH, DR, BS, PS, KT, MB:** Received consultancy fees from Traverre Therapeutics, Inc.
- **BH:** Employee, Traverre Therapeutics, Inc.
- **WT, MZ, Z-YZ:** Employees of Analysis Group, which received consultancy fees from Traverre Therapeutics, Inc.

- While IgAN has been shown to be associated with significant clinical and economic impact, less is known about the humanistic burden associated with the disease
- HONUS (**H**umanistic Burden **o**f Rare **N**ephrotic Diseases: **U**nderstanding the impact of FSGS and IgAN on Patients and Caregivers **S**tudy) is a multi-national, cross-sectional survey designed in consultation with IgAN and FSGS patients and clinical community members
- The HONUS study aims to quantify the humanistic burden of rare kidney diseases from both patient and caregiver (care-partner) perspectives¹
- The current analysis focused on a subset of IgAN adult patients and their care-partners in the United States (US) who participated in HONUS before September 2022

Objectives:

- To quantify the humanistic burden of IgAN adult patients in the US
- To understand the burden and impact of IgAN from the care-partner perspective

FSGS, focal segmental glomerulosclerosis; IgAN, immunoglobulin A nephropathy.

1. Szklarzewicz J, et al. Poster presented at the American Society of Nephrology's Kidney Week. 2021;abstract PO1479.

- Patients and care-partners were recruited from two patient advocacy groups (NephCure Kidney International and the IGA Nephropathy Foundation of America) and one medical center (University of North Carolina Kidney Center) in the US

Study Outcomes

- The following data were collected among patients and care-partners:

Patient	Care-partner
<ul style="list-style-type: none"> ▪ KDQoL-36 ▪ GAD-7 ▪ PHQ-9 ▪ Most burdensome symptoms ▪ Fear and uncertainty for the future ▪ Productivity impairment: WPAI:SHP 	<ul style="list-style-type: none"> ▪ SF-12 ▪ GAD-7 ▪ PHQ-9 ▪ Fear and uncertainty for the future ▪ Productivity impairment: WPAI:SHP

Kidney Disease Quality of Life Instrument (KDQoL-36) is a short form that includes the SF-12 as generic core plus the burden of kidney disease, symptoms/problems of kidney disease, and effects of kidney disease scales from the KDQOL-SF™v1.3¹

12-Item Short Form Survey (SF-12) is a general health questionnaire that assesses the impact of health on everyday life²

Generalized Anxiety Disorder Assessment (GAD-7) is a seven-item instrument that is used to measure or assess the severity of generalized anxiety disorder³

Patient Health Questionnaire-9 (PHQ-9) is the 9-item depression module from the full PHQ and measures the severity of depression⁴

Work Productivity and Activity Impairment Questionnaire: Specific Health Problem (WPAI:SHP)⁵

1. Hays RD. *J Behav Med.* 1994;17:361-7; 2. Mark Kosinski JEW, et al (eds). *User's manual for the SF-12v2 health survey: with a supplement documenting the SF-12® health survey.* QualityMetric Incorporated, Lincoln, RI;2007; 3. Spitzer RL, et al. *Arch Int Med.* 2006;166(10):1092-1097; 4. Kroenke K, et al. *J Gen Int Med.* 2001;16(9):606-613; 6. Reilly MC, et al. *Pharmacoeconomics.* 1993;4(5):353-365.

Table 1. Demographics for patients and care-partners

	Patients (N=89)	Care-partners (N=89)
Age		
Mean ± SD	37.3 ± 8.1	39.6 ± 11.0
Median	35.0	36.0
Sex, N (%)		
Male	46 (51.7)	40 (44.9)
Female	42 (47.2)	48 (53.9)
Other/Unknown	1 (1.1)	1 (1.1)
Race, N (%)		
Caucasian	77 (86.5)	79 (88.9)
African American	7 (7.9)	7 (7.9)
Hispanic	3 (3.4)	3 (3.4)
Asian and Pacific Islander	2 (2.3)	2 (2.3)
Native American	1 (1.1)	0 (0.0)
Prefer not to answer	1 (1.1)	0 (0.0)
Employment status, N (%)		
Full time	61 (68.5)	77 (86.5)
Part time	5 (5.6)	6 (6.7)
Self employed	0 (0.0)	1 (1.1)
Looking for work	12 (13.5)	1 (1.1)
Not looking for work	6 (6.7)	0 (0.0)
Retired	0 (0.0)	1 (1.1)
Disability	2 (2.3)	0 (0.0)
Student	1 (1.1)	1 (1.1)
Homemaker	2 (2.3)	2 (2.3)

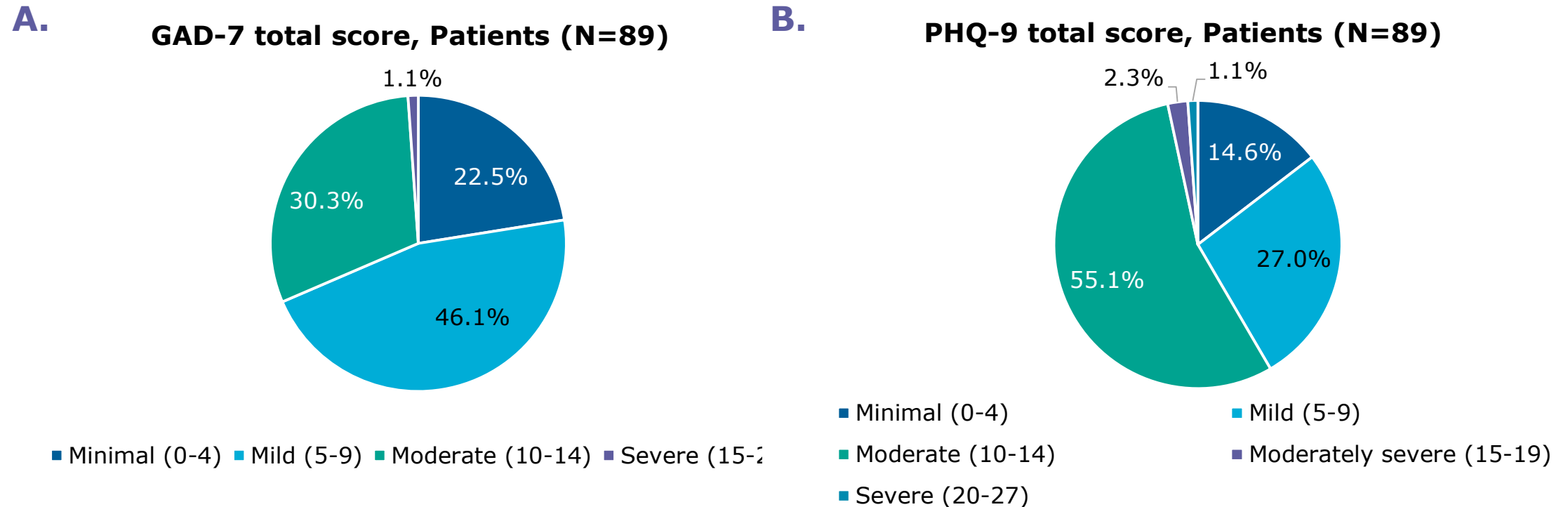
SD, Standard deviation.

Table 2. QOL for patients and care-partners

	Patients (N=89)	Care-partners (N=89)
SF-12 PCS		
Mean ± SD	46.8 ± 7.0	50.0 ± 6.6
Median	47.5	49.4
SF-12 MCS		
Mean ± SD	40.4 ± 8.5	42.7 ± 9.6
Median	40.1	41.1
Burden of kidney disease (KDQoL-36)		
Mean ± SD	44.6 ± 22.0	-
Median	37.5	-
Symptom/problems (KDQoL-36)		
Mean ± SD	59.6 ± 14.0	-
Median	56.3	-
Effects of kidney disease (KDQoL-36)		
Mean ± SD	64.0 ± 15.9	-
Median	62.5	-

KDQoL, kidney disease quality of life instrument; MCS, mental component summary; PCS, physical component summary; SD, standard deviation; SF-12, 12-item short form survey.

Figure 1. GAD-7 and PHQ-9 total scores - Patients



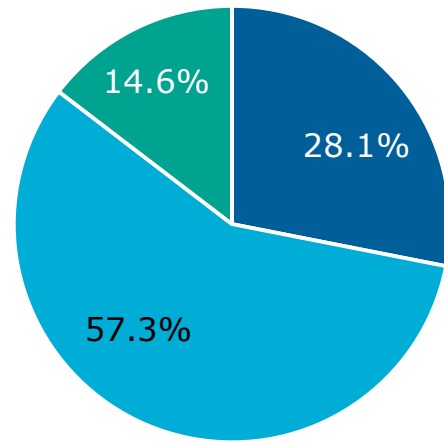
GAD-7, general anxiety disorder-7; PHQ-9, patient health questionnaire-9.

1. GAD-7 is calculated by assigning scores of 0, 1, 2, and 3 to the response categories, respectively, of "not at all," "several days," "more than half the days," and "nearly every day." GAD-7 total score for the seven items ranges from 0 to 21. 0-4 indicates minimal anxiety, 5-9 indicates mild anxiety, 10-14 indicates moderate anxiety and 15-21 indicates severe anxiety. The recall period is the past 2 weeks.

2. PHQ-9 scores are calculated based on how frequently a person experiences these feelings. Each "not at all" response is scored as 0; each "several days" response is 1; each "more than half the days" response is 2; and each "nearly every day" response is 3. The sum value of these responses gives the total score. 0-4 indicates minimal depression, 5-9 indicates mild depression, 10-14 indicates moderate depression, 15-19 indicates moderately severe depression, and 20-27 indicates severe depression. The recall period is the past 2 weeks.

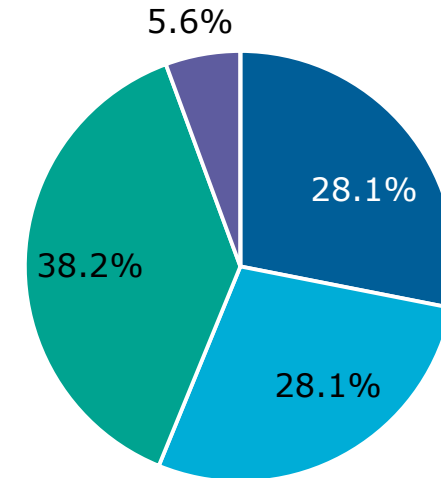
Figure 1. GAD-7 and PHQ-9 total scores – Care-partners

C. GAD-7 total score, Care-partners (N=89)



■ Minimal (0-4) ■ Mild (5-9)
■ Moderate (10-14)

D. PHQ-9 total score, Care-partners (N=89)



■ Minimal (0-4) ■ Mild (5-9)
■ Moderate (10-14) ■ Moderately severe (15-19)

GAD-7, general anxiety disorder-7; PHQ-9, patient health questionnaire-9.

1. GAD-7 is calculated by assigning scores of 0, 1, 2, and 3 to the response categories, respectively, of “not at all,” “several days,” “more than half the days,” and “nearly every day.” GAD-7 total score for the seven items ranges from 0 to 21. 0–4 indicates minimal anxiety, 5–9 indicates mild anxiety, 10–14 indicates moderate anxiety and 15–21 indicates severe anxiety. The recall period is the past 2 weeks.

2. PHQ-9 scores are calculated based on how frequently a person experiences these feelings. Each “not at all” response is scored as 0; each “several days” response is 1; each “more than half the days” response is 2; and each “nearly every day” response is 3. The sum value of these responses gives the total score. 0–4 indicates minimal depression, 5–9 indicates mild depression, 10–14 indicates moderate depression, 15–19 indicates moderately severe depression, and 20–27 indicates severe depression. The recall period is the past 2 weeks.

Table 3. WPAI:SHP

	Patients (N=89)	Care-partners (N=89)
Number of people with working hours in the past 7 days, N (%)	65 (73.0)	84 (94.4)
Percent absenteeism		
Mean ± SD	6.7 ± 8.1	10.5 ± 15.0
Median	4.8	5.1
Percent presenteeism		
Mean ± SD	28.0 ± 22.4	29.2 ± 22.6
Median	30.0	30.0
Percent overall work impairment		
Mean ± SD	32.2 ± 23.7	35.4 ± 25.9
Median	31.8	33.3
Percent activity impairment		
Mean ± SD	37.8 ± 22.6	34.0 ± 24.7
Median	30.0	30.0

SD, standard deviation; WPAI:SHP, work productivity and activity impairment:specific health problem.

1. Percent absenteeism, percent presenteeism, and overall work impairment were only assessed among respondents who were employed at the time of survey.
2. One patient is employed, but worked 0 hours in the past week, so percent work time missed, impairment while working, and overall work impairment were not available for that patient.
3. The recall period is the past 7 days.

- Adult patients with IgAN in the US experienced impaired mental and physical health compared with the general population. The disease negatively impacted their work productivity.
- Care-partners for adult patients with IgAN had considerably worse mental health compared with the general population. Their work productivity was also impaired due to the disease.