



Scan to obtain:
• Poster

<https://bit.ly/IKCWCN>
Copies of this poster obtained through Quick Response (QR) code are for personal use only and may not be reproduced without permission of the authors.

Self-reported quality of life in complement 3 glomerulopathy patients delineated by CKD stage: a real-world, multi-country survey

Raisa Sidhu¹, Clare Proudfoot¹, Katharina Pannagl², Briana Ndife³, Serge Smeets¹, Kathleen Murphy³, Raymond Przybysz³, Jonathan de Courcy⁴, Susanna Libby⁴, Smeeta Sinha^{5,6}, Richard Lafayette⁷

¹Novartis Pharma AG, Basel, Switzerland; ²Novartis Pharmaceuticals UK Ltd, London, UK; ³Novartis Pharmaceuticals Corporation, East Hanover, New Jersey, United States; ⁴Adelphi Real World, Bollington, UK; ⁵Northern Care Alliance NHS Foundation Trust, Salford, UK; ⁶Manchester Academic Health Science Centre (MAHSC), University of Manchester, Manchester, UK; ⁷Stanford University Medical Center, United States

CONCLUSIONS

- C3G was shown to have a debilitating impact on a patient's quality of life, in particular, due to fatigue which was described as the second most distressful symptom. Distress to patients was also caused by foamy urine and swollen hands/feet/ankles.
- Quality of life was notably lower for patients with stage 4/5 of CKD.
 - Patients in CKD stages 4 or 5 scored notably lower for both the EQ-VAS and EQ-5D-5L.
 - Lowest FACIT-Fatigue scores were reported for patients in CKD stages 4 and 5.
- Targeted treatment to slow the progression of kidney disease in C3G patients could delay the impact of C3G and help improve patients' quality of life at early stages.

Poster Presented at the World Congress of Nephrology (WCN), April 13–16, 2024.

INTRODUCTION

- Complement 3 glomerulopathy (C3G) is a rare kidney disease, with an estimated worldwide incidence of 1-2 million people/year¹.
- It is characterized by the dysregulation of the alternative pathway of the complement system, resulting in C3 deposition in the glomeruli².
- The disease is associated with a high risk of disease progression and later stages are associated with worsening symptoms³.
- Limited published data is available describing the health-related quality of life in patients with C3G.

OBJECTIVE

- This analysis aimed to evaluate the impact of CKD stage on the health-related quality of life in a multi-country study of C3G patients.

METHODS

- Data were drawn from the Adelphi C3G Disease Specific Programme™ (DSP), a cross-sectional survey of C3G-treating nephrologists which included the capture of retrospective data.
- Data were collected in France, Germany, Italy, Spain, the United Kingdom (EU5), China, Japan and the United States (US) from August 2022 – April 2023.
- Nephrologists who agreed to participate in the C3G DSP completed forms for between 1-9 consecutively consulting C3G patients, reporting demographic and clinical information including CKD stage by glomerular filtration rate.

- These patients were then invited to voluntarily complete a survey, self-reporting impact of fatigue within the last seven days via the Functional Assessment of Chronic Illness Therapy (FACIT) – Fatigue and health-related quality of life via the EQ-5D-5L (US tariff), the EuroQol Visual Analogue Scale (EQ-VAS). The survey also included symptoms experienced at time of survey and which symptom(s) were the most bothersome at the time of survey.

- Descriptive analyses were performed on all data.

LIMITATIONS

- Patients included in the DSP sample are the next eligible patients who consult the participating physician and therefore, may not truly represent the overall population of patients with C3G in their country/region.
- Some of the results presented are based on small samples and should be interpreted with appropriate caution.

RESULTS

Patient characteristics

- In total, 111 nephrologists provided data for 385 patients (EU n=189, China n=60, Japan n=36, US n=100), of which 344 (89.4%) had a known CKD stage.
- Of these 385 patients, 100 (26.0%) completed a patient survey (EU5 n=29, China n=55, Japan n=5, US n=11).
- Median (IQR) patient age at time of survey was 41.5 (32.0-54.0) years and 63.0% were male. Where reported [n=99 (25.7%)], patients have been diagnosed with C3G for a median (IQR) of 1.9 (0.9-3.9) years (Table 1).

CKD stages at diagnosis and time of survey

- Patient CKD stages are shown in Table 1; due to sampling limitations stages 4 and 5 were combined for analysis

Fatigue

- C3G patients reported higher levels of fatigue (FACIT-fatigue score of 30.3) than the mean general population score of 43.5⁵ indicating severe fatigue (FACIT-fatigue scores range from 0-51 with lower scores indicating more severe fatigue) among them. Scores were notably lower for patients at stages 4/5 dropping to 27.8 (Figure 1), 36.1% worse than the general population.

Figure 1. Mean FACIT-fatigue score by CKD Stage

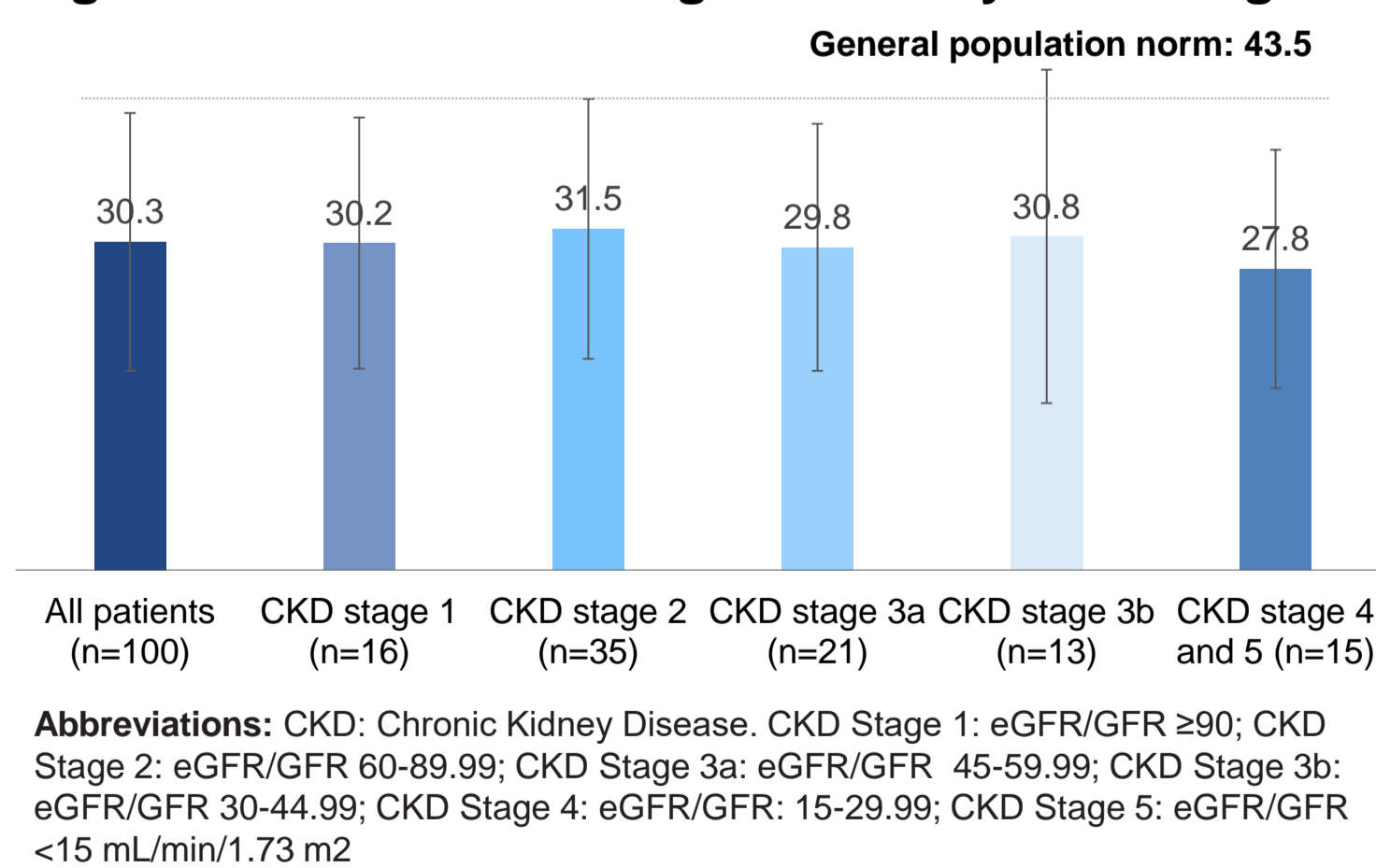
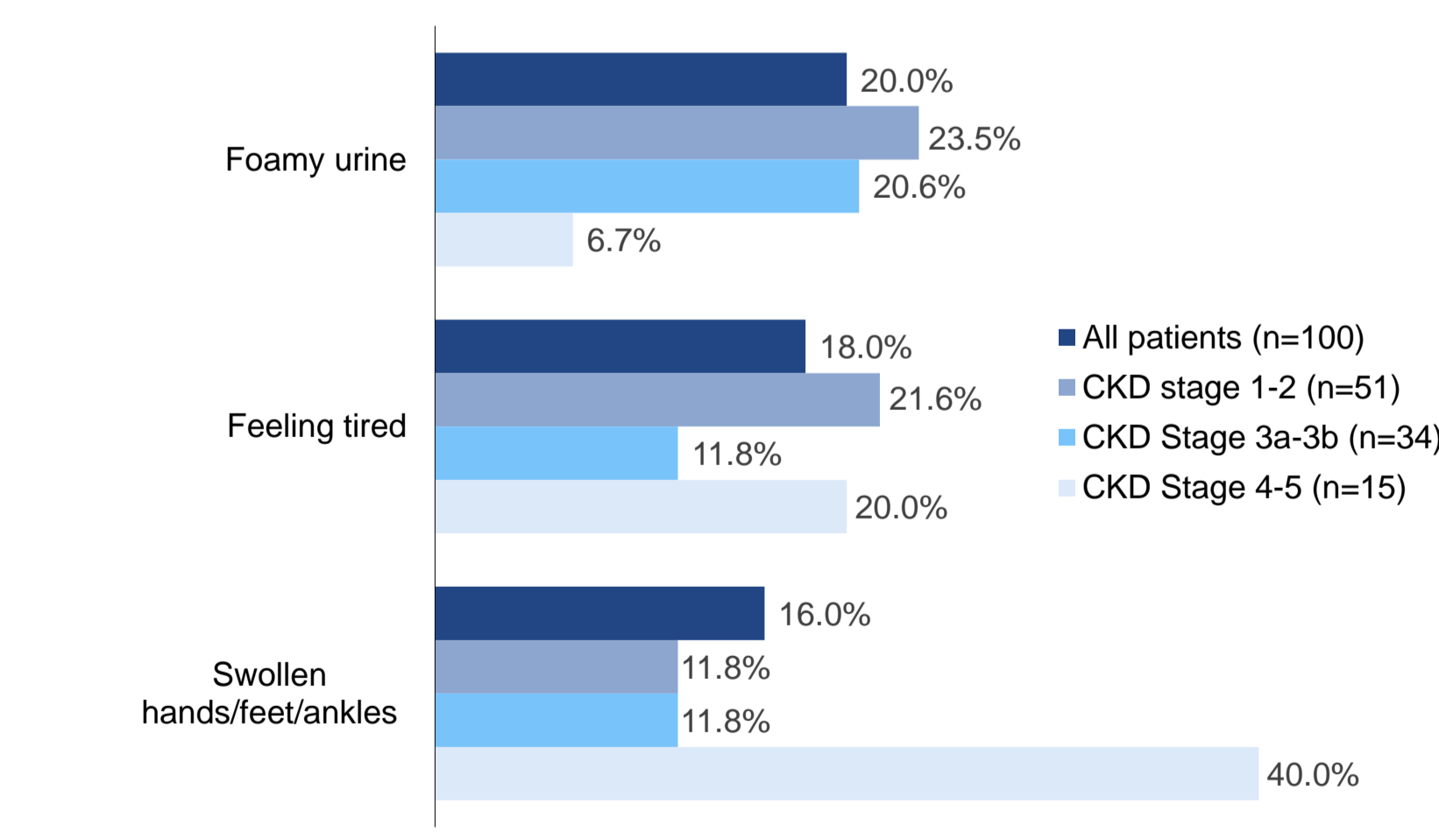


Table 1. Patient characteristics of C3G patients

	All patients	CKD 1	CKD 2	CKD 3a	CKD 3b	CKD 4 & 5
N	100	16	35	21	13	15
Age at time of survey, median (IQR)	41.5 (32.0-54.0)	35.0 (32.0-45.0)	35.0 (24.0-40.0)	50.0 (37.5-56.5)	53.0 (33.0-64.5)	56.0 (44.0-69.0)
Male patients, n (%)	63 (63.0)	10 (62.5)	21 (60.0)	14 (66.7)	6 (46.2)	12 (80.0)
Working full time or part-time, n (%)	54 (54.0)	13 (81.2)	18 (51.4)	16 (76.2)	2 (15.4)	5 (33.3)
Time since diagnosis, median years (IQR)	1.9 (0.9-3.9)	1.1 (0.1-6.3)	2.1 (1.2-4.0)	1.4 (0.5-4.1)	1.9 (1.4-2.5)	2.2 (1.5-5.9)

Figure 2. Top 3 most distressful symptoms at the time of survey by CKD stage



Abbreviations: CKD Stage 1: eGFR/GFR ≥90; CKD Stage 2: eGFR/GFR 60-89.99; CKD Stage 3a: eGFR/GFR 45-59.99; CKD Stage 3b: eGFR/GFR 30-44.99; CKD Stage 4: eGFR/GFR: 15-29.99; CKD Stage 5: eGFR/GFR <15 mL/min/1.73 m²; IQR: Interquartile ranges

- 'Feeling tired' (Figure 2) was ranked as the second most distressful symptom (18.0%) by C3G patients, surpassed only by 'foamy urine' (20.0%).

EQ-5D

- Patient EQ-VAS scores ranged from 46.8 to 66.7, lower than the mean general population score of 78.16 (lower scores indicate poorer quality of life).
 - CKD stage 1 patients reported a low score of 63.6.
 - CKD stages 1-3b reported similar scores, however at CKD stage 4/5 patients reported the lowest score of 46.8 (Figure 3a), 40.1% worse than the general population.
- C3G patients also experienced worse EQ-5D utility scores compared to the mean general population score of 0.84; CKD Stage 1 patients had a mean score of 0.67; Stage 4/5 patients had a lower mean score of 0.58 (Figure 3b).

Figure 3a. Mean EQ-VAS score by CKD stage

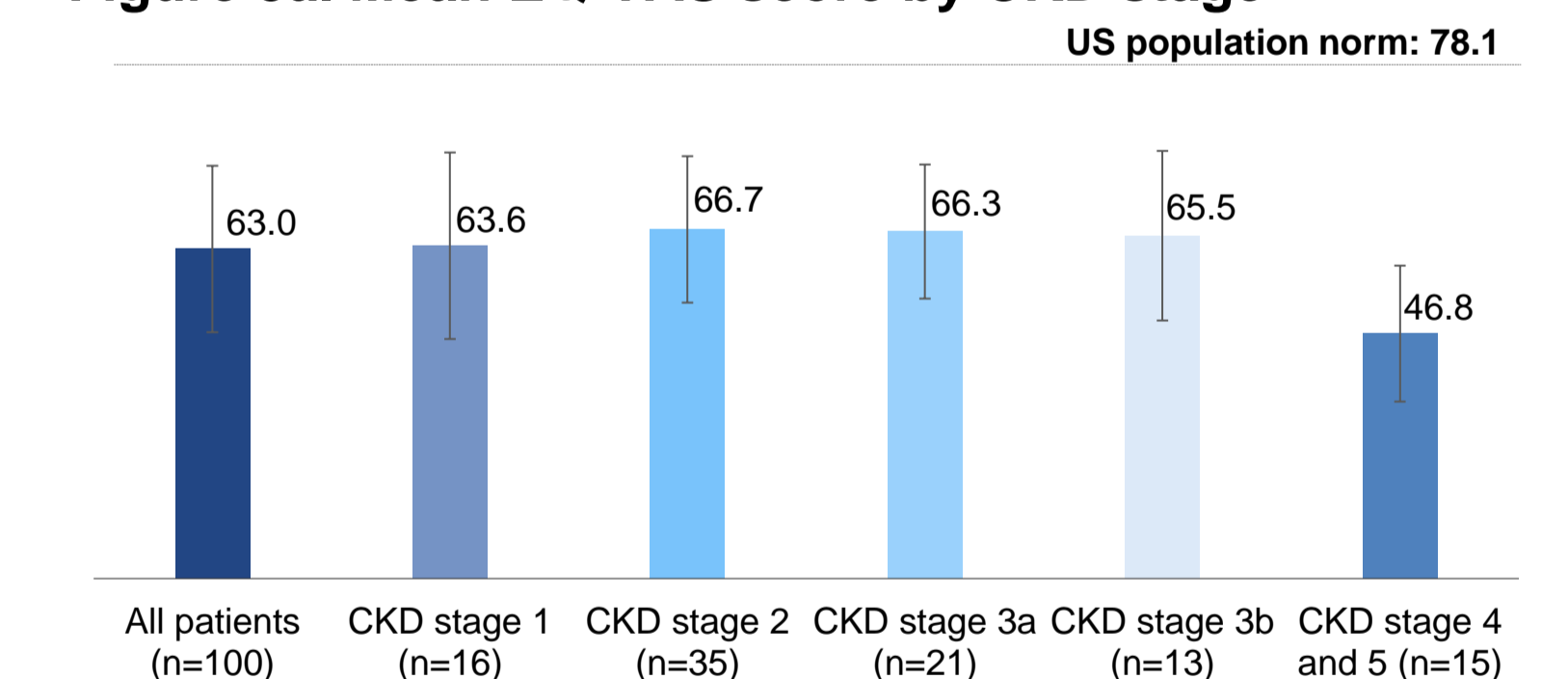
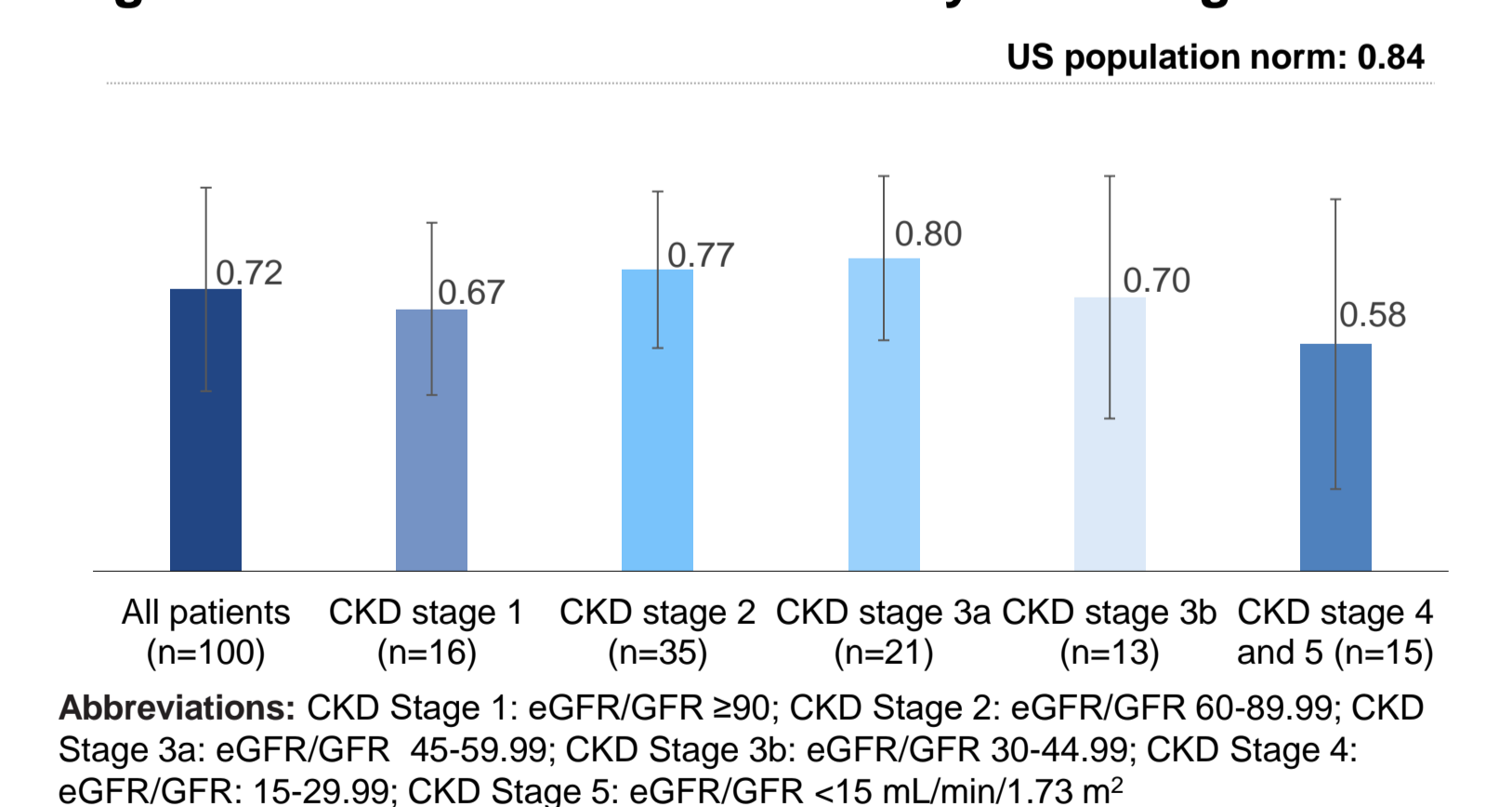


Figure 3b. Mean EQ-5D-5L score by CKD stage



Acknowledgments

Editorial assistance under the guidance of the authors was provided by Alice Simons and Laurretta Birija of Adelphi Real World

Disclosures

- The authors had full editorial control of the poster and provided their final approval of all content.
- Data collection for the DSP was undertaken by Adelphi Real World as part of an independent survey and data is owned by Adelphi.
- Novartis is one of multiple subscribers to the DSP and supported this analysis.
- This study was funded by Novartis Pharma AG and several authors are employees/shareholders of Novartis Pharma AG.

References

1. Medjeral-Thomas NR et al. C3 glomerulopathy: clinicopathologic features and predictors of outcome. Clinical Journal of the American Society of Nephrology. 2014 Jan 7;9(1):46-53.
2. Smith RJH, Appel GB, Blom AM, et al. C3 glomerulopathy - understanding a rare complement-driven renal disease. Nat Rev Nephrol. 2019;15(3):129-143. doi:10.1038/s41581-018-017-2
3. Smith RJ et al. C3 glomerulopathy-understanding a rare complement-driven renal disease. Nature reviews nephrology. 2019 Mar;15(3):129-43.
4. Anderson P, Benford M, Harris N, Karavali M, Piercy J. Real-world physician and patient behaviour across countries: Disease-Specific Programmes™ a means to understand. Current Medical Research and Opinion. 2008; 24(11):3063-3072.
5. Montan, Inka et al. "General Population Norms for the Functional Assessment of Chronic Illness Therapy (FACIT)-Fatigue Scale." Value in health : the journal of the International Society for Pharmacoeconomics and Outcomes Research vol. 21,11 (2018): 1313-1321. doi:10.1016/j.jval.2018.03.013
6. Jiang, R., Janssen, M.F.B. & Pickard, A.S. US population norms for the EQ-5D-5L and comparison of norms from face-to-face and online samples. Qual Life Res 30, 803–816 (2021). <https://doi.org/10.1007/s11136-020-02650-y>