

Patient-Reported Experience of Diagnosis, Management, and Burden of Renal Cell Carcinomas: Results from a Global Patient Survey in 43 countries

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Abstract

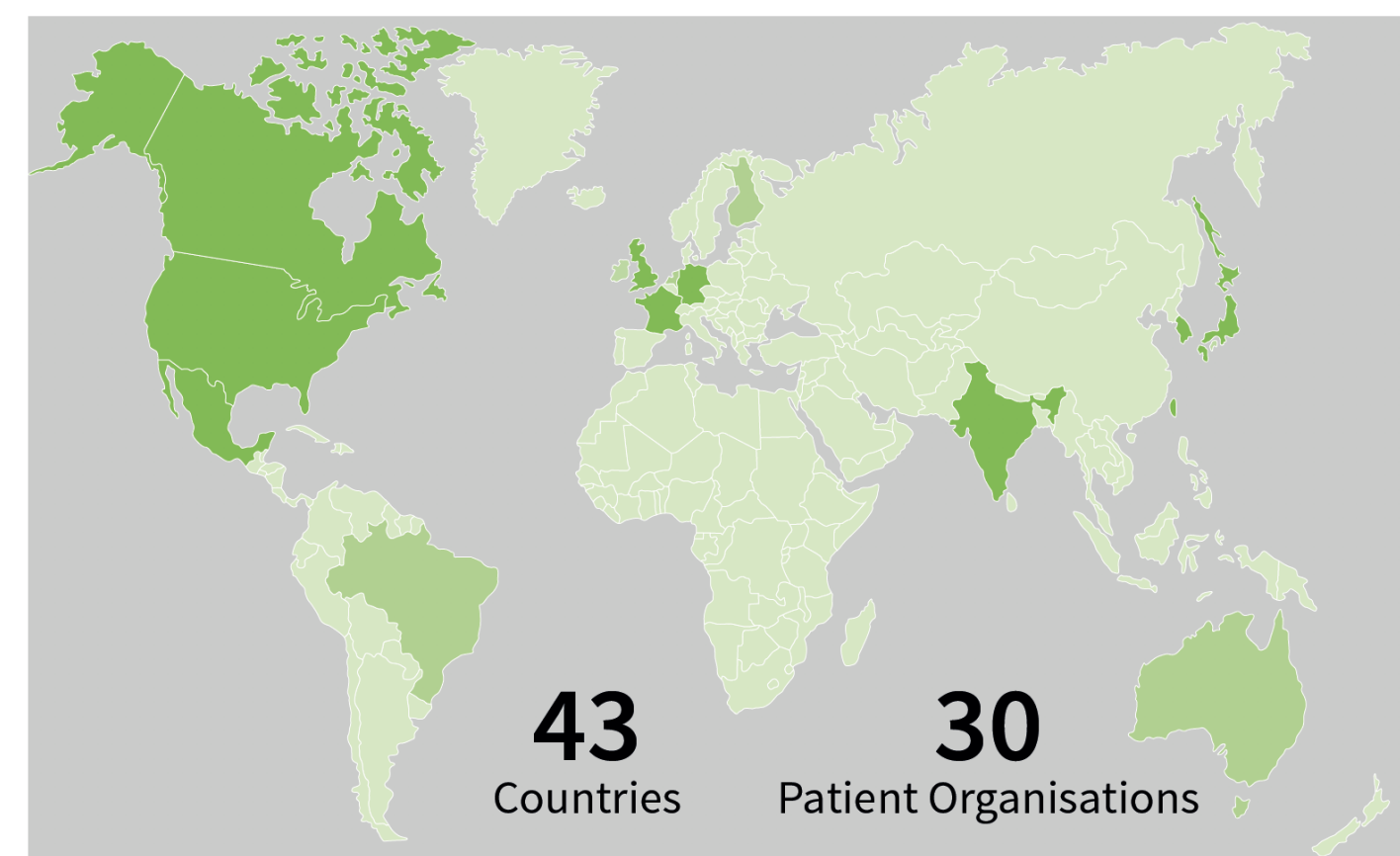
Background: The International Kidney Cancer Coalition (IKCC) is a federation of 38 affiliated patient organisations representing 1.2 million patients worldwide, committed to reduce the global burden of kidney cancer. A large-scale global survey of RCC patients to capture real world experiences has never been undertaken. **Methods:** The 35-question survey was designed to identify geographic variations in patient education, experience and awareness, access to care, best practices, quality of life and unmet psychosocial needs. It was completed online or in paper form by kidney cancer patients and /or their caregivers (Sept-Oct 2018). **Results:** 1,983 responses were recorded from 43 countries in 14 languages. Analysis revealed that at diagnosis, 43% of all respondents had no understanding of their RCC sub-type; RCC patients < 45 years old reported nearly twice as many barriers to treatment as patients > 45 at diagnosis. Females reported longer delays to diagnosis than males. Shared decision making remains aspirational: globally 29% of all patients reported no involvement in their treatment decision, responding ‘my doctor decided for me’. While 96% of respondents reported psychosocial impacts, surprisingly, only 50% disclosed them to their healthcare team. Most difficult times experienced by patients varied by gender and by country.

RESULTS

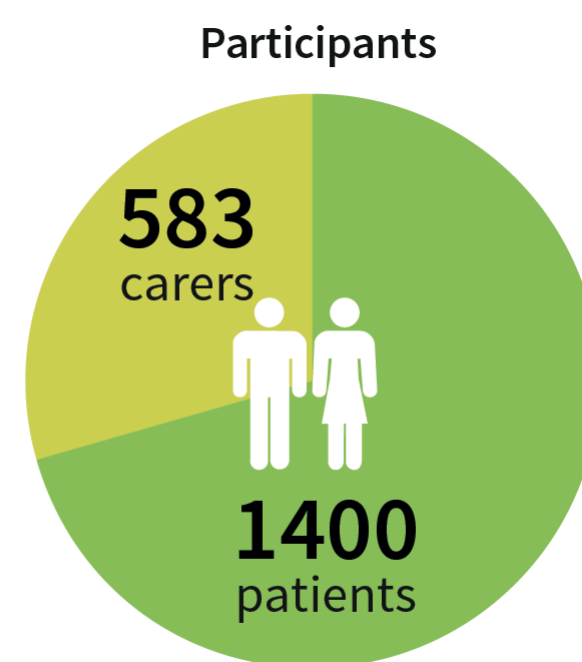
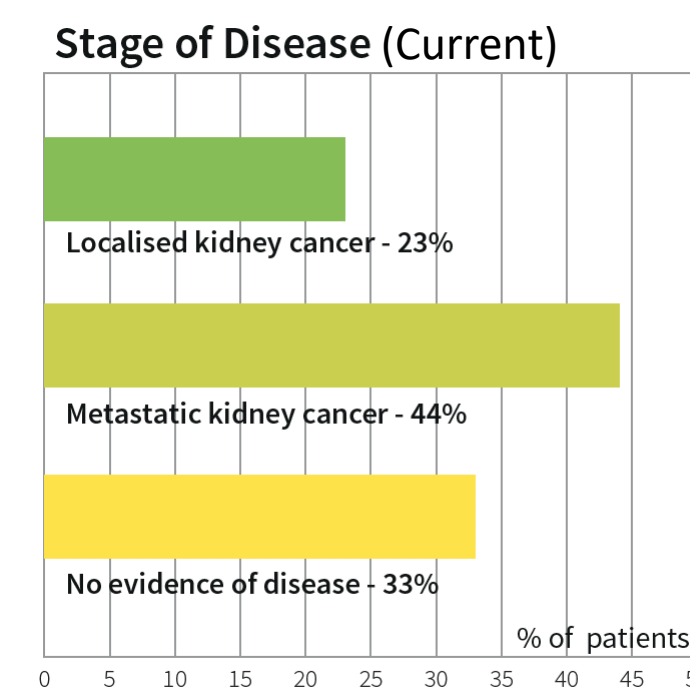
Patient Characteristics



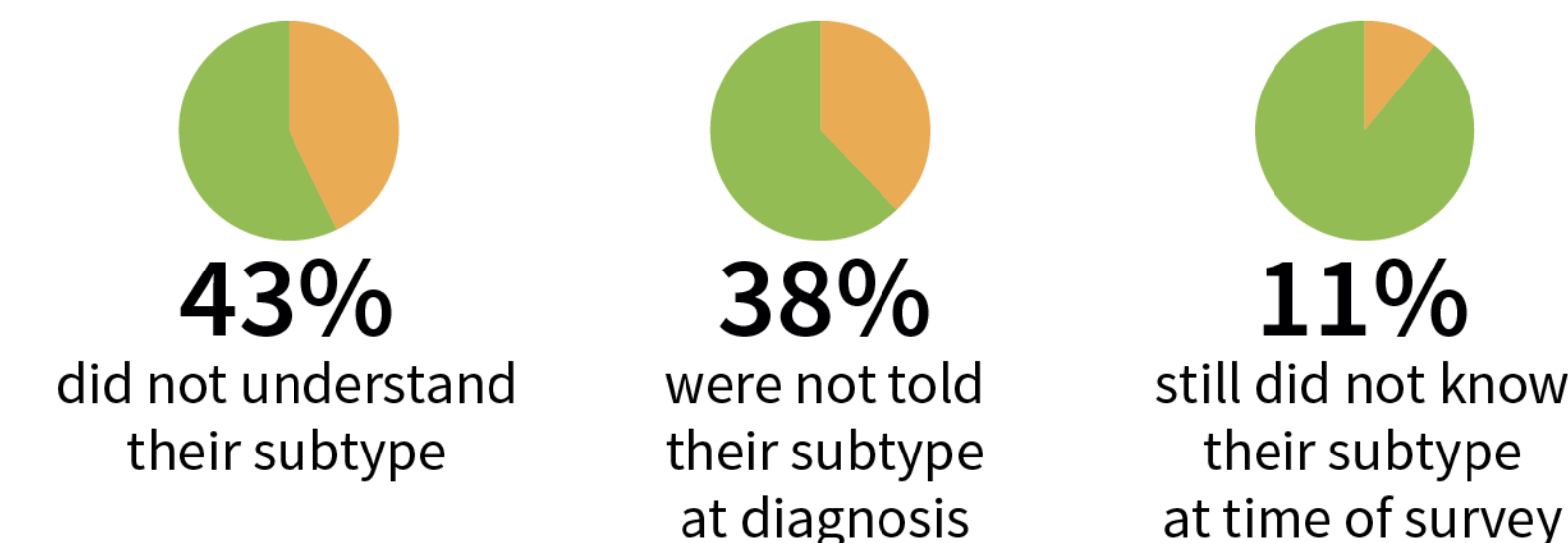
Total Global Participants:
1983



The Global Patient Survey included respondents from Canada (12%), France (12%), the United States (12%), South Korea (12%), Japan (10%), the United Kingdom (9%), Mexico (7%), India (7%), Germany (6%), Brazil (3%), The Netherlands (2%), Australia (2%), Finland (2%), Other (4%).

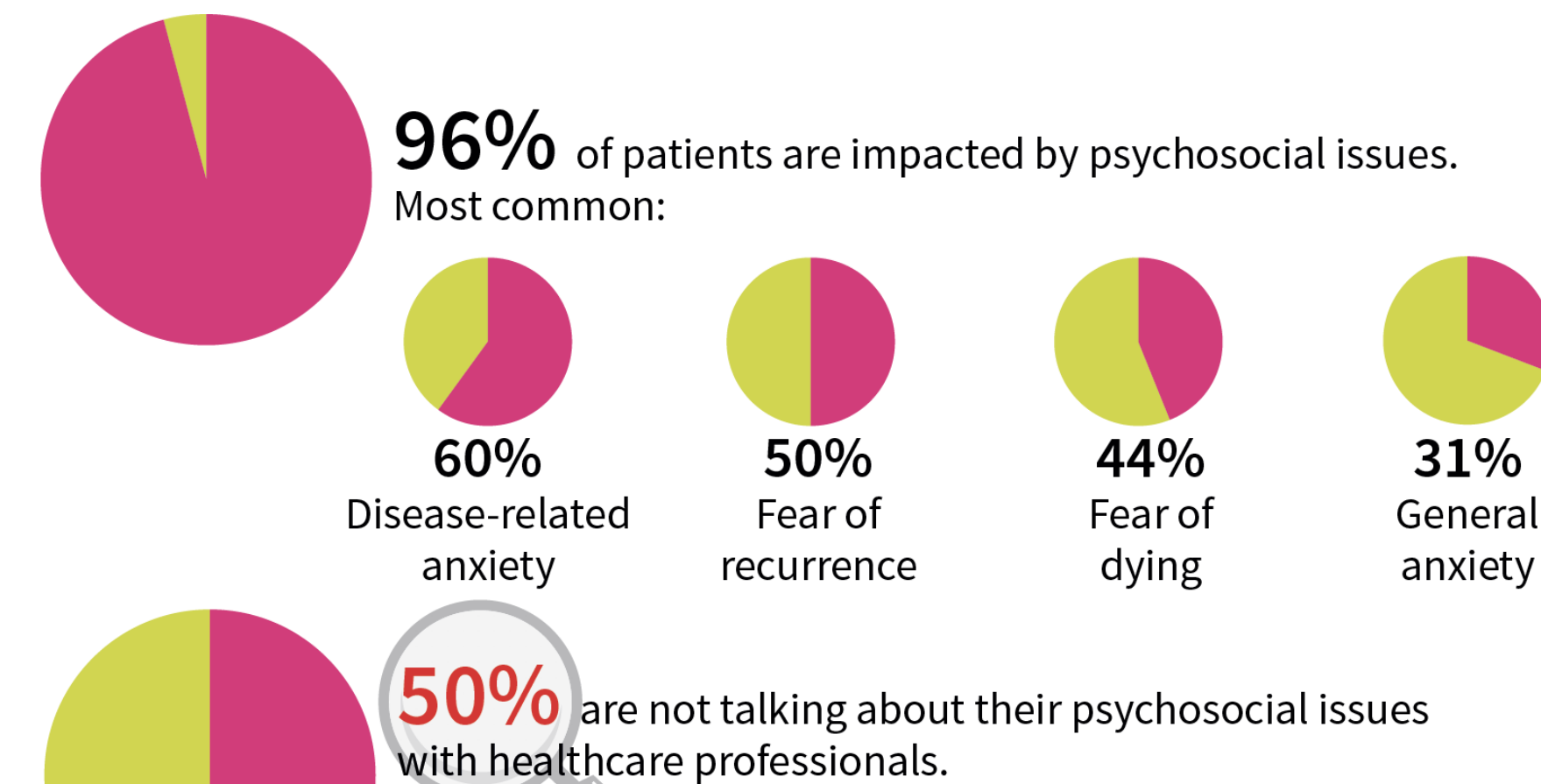


Knowledge and Understanding of Diagnosis

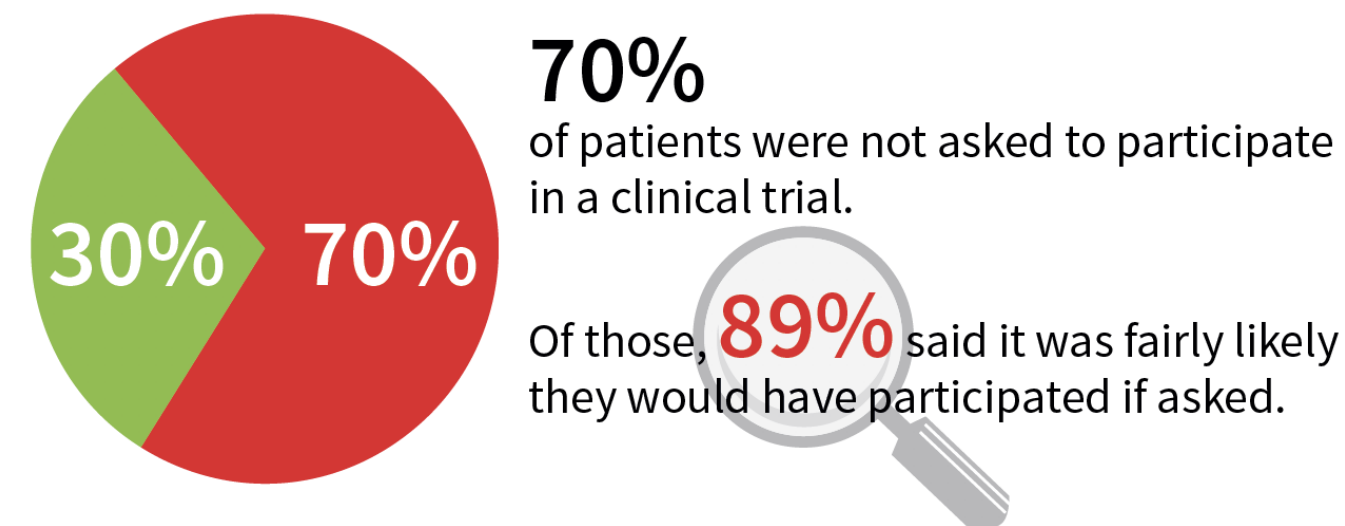


RESULTS

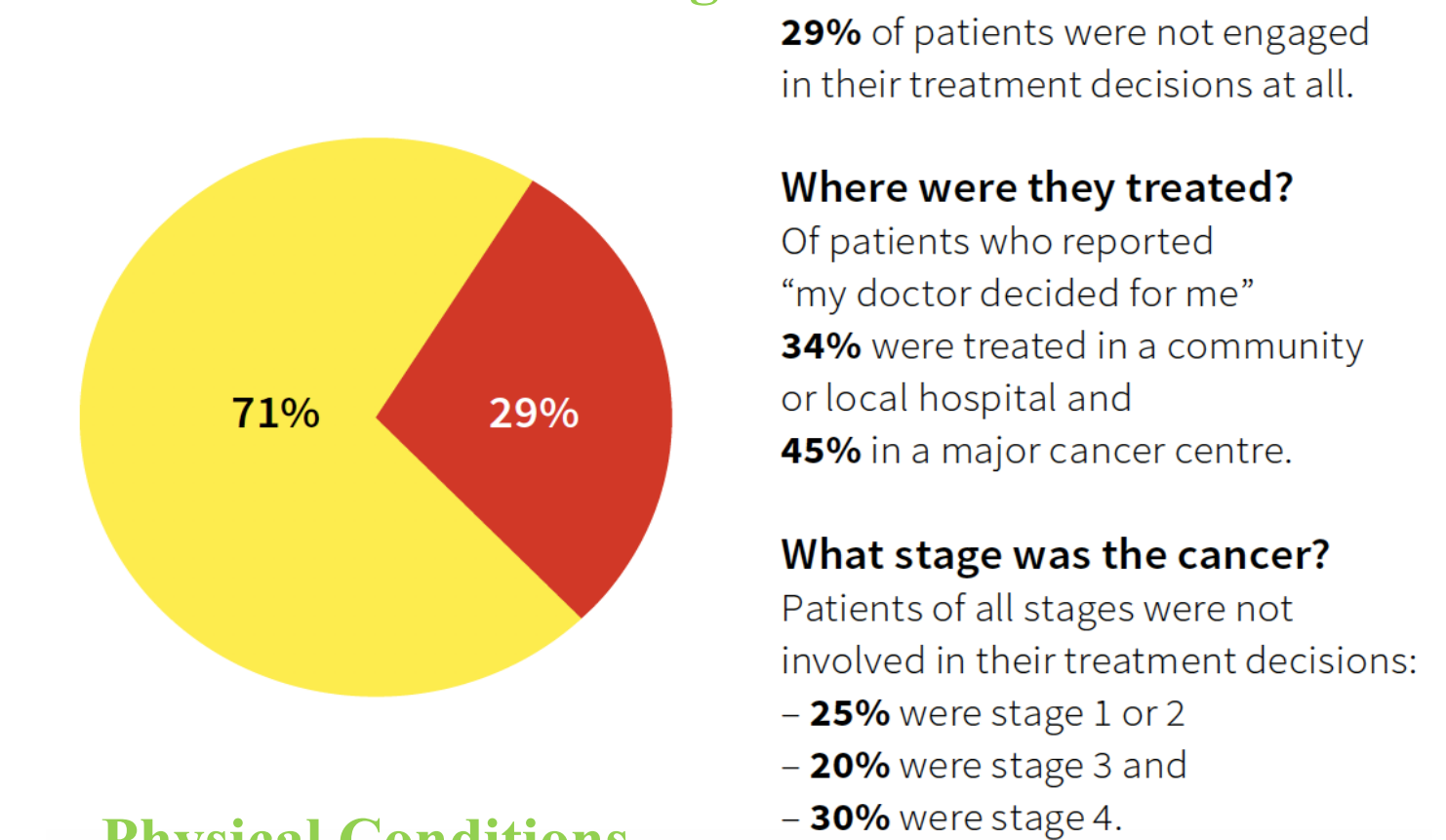
Psychosocial Issues



Clinical Trials

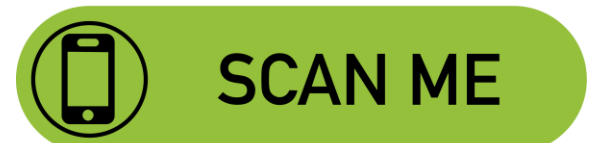
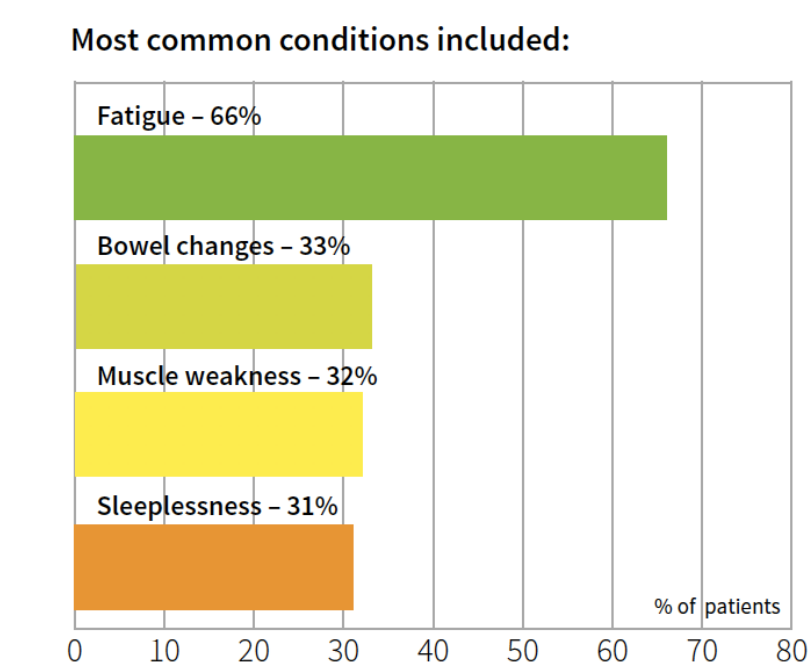


Shared Decision Making



Physical Conditions

92% of patients said their physical well-being was impacted since the initial diagnosis.



CONCLUSIONS

This research sheds light on the unmet needs in the RCC patient experience and highlights improvements to the design and delivery of supportive care. This first-ever global survey serves as a benchmark for longitudinal data collection and could be used to inform future disease-specific quality of life instruments.

Conflict of Interest

This project was funded with sponsorship from the following companies in full compliance with the IKCC Code of Conduct: BMS, Ipsen, Novartis, Pfizer, Roche. Data was independently analyzed by Perception Insight.

