

Concordance between patient and physician reporting of symptoms for metastatic urothelial cancer in Europe: a real-world survey

M. Unsworth,¹ C. Forshaw,¹ M. Walley,¹ H. Wear,¹ A. Simpson,¹ M. Kearney²

¹Adelphi Real World, Bollington, UK; ²Merck Healthcare KGaA, Darmstadt, Germany

CONCLUSIONS

- This study assessed patient- and physician-reported symptoms of metastatic urothelial carcinoma (mUC) and their concordance in Europe
- Patients most commonly were older, male, and had a history of smoking. At initial diagnosis of UC, tumors were most commonly located in the bladder, with approximately two-thirds of these patients being diagnosed at the metastatic stage
- Fatigue/lack of energy was frequently reported at both mUC diagnosis and the time of data collection by both patients and physicians
 - Specifically, it was the most frequently reported symptom by both patients and physicians at data collection and showed moderate physician-patient concordance
- Fair to moderate patient-physician alignment was reported across all symptoms
- Measures of pain such as pelvis, bladder, and back pain all showed moderate agreement
- Low agreement was observed for symptoms that patients may be embarrassed to report, such as urinary urgency and feeling the need but not being able to urinate
- The lack of agreement between physicians and patients highlights the importance of proper evaluation of symptom burden in patients with mUC to inform treatment strategies that consider quality of life. Future studies should also be directed toward understanding overall quality of life for patients with mUC¹

PLAIN LANGUAGE SUMMARY

- Metastatic urothelial cancer (mUC) is an advanced form of bladder cancer that mostly affects older people, impacting their quality of life
- We wanted to see to what extent physicians and patients reported the same symptoms, using a survey of mUC-treating physicians and their patients in France, Germany, Italy, Spain, and the UK between December 2023 and July 2024
- Feeling tired was reported as a symptom by the majority of patients and physicians at both mUC diagnosis and data collection
- For all symptoms, only fair to moderate agreement between physicians and patients was seen, with worse agreement for embarrassing symptoms such as needing to use the toilet frequently
- It is important that physicians understand patient symptoms so that these can be considered when choosing the most appropriate treatments that support quality of life

BACKGROUND

- UC is the 10th most common cancer globally, primarily affecting the older population (≥ 65 years old)?
- mUC is an advanced stage of the disease associated with poor outcomes, with a 5-year survival rate of $< 5\%$ ²
- However, the treatment landscape for mUC in Europe is rapidly evolving, with recent approvals for treatments such as avelumab maintenance therapy, enfortumab vedotin in combination with pembrolizumab, and more recently cisplatin + gemcitabine in combination with nivolumab followed by nivolumab maintenance therapy^{3,4}
- When making treatment decisions, it is important for physicians to not only consider the evolving treatment landscape but to also consider patient symptoms, with a focus on patient quality of life
- There is a lack of real-world data on physician awareness of patient symptoms. Thus, we aimed to explore patient and physician concordance regarding symptom perception in Europe

RESULTS

- Overall, 97 physicians reported data for 442 patients with mUC (Table 1)
- Mean (SD) patient age was 68.8 (8.3) years; 68% of patients were male, and 63% were former smokers (Table 1)
- At data collection, the majority of patients (71%) were retired, and 62% of patients had a caregiver (Table 1)
- At initial UC diagnosis, 87% had a tumor located in the bladder; of these patients, 61% were diagnosed with metastatic disease. For the remainder of patients, 6%, 6%, and 1% had an initial tumor in the ureter, renal pelvis, and urethra, respectively (Table 2)
- At diagnosis, physicians most commonly reported fatigue/lack of energy (54%), hematuria/blood or blood clots in the urine (48%), and urinary dysuria (39%). Patients self-reported hematuria/blood or blood clots in the urine (57%), urinary dysuria (45%), fatigue/lack of energy (44%), and frequent need to urinate (44%) as the most common symptoms at diagnosis (Figure 1)
- At data collection, physicians reported that patients were most commonly experiencing fatigue/lack of energy (68%), muscle aches/weakness (29%), and pelvis pain (28%). Patients self-reported fatigue/lack of energy (64%), back pain/pain (36%), and muscle aches/weakness (35%) as the 3 most common symptoms (Figure 1)
- Moderate agreement was observed for measures of pain, such as flank pain/pain (k=0.455; p<0.0001), back pain/pain (k=0.413; p<0.0001), bladder pain (k=0.466; p<0.0001), and muscle aches/weakness (k=0.454; p<0.0001). Moderate agreement was also seen for fatigue/lack of energy (k=0.460; p<0.0001) and hematuria/blood or blood clots in the urine (k=0.423; p<0.0001) (Table 3)
- Fair agreement was observed for urinary symptoms such as frequent need to urinate (k=0.393; p<0.0001), feeling the need to urinate but not being able to pass urine (k=0.288; p<0.0001), and urinary urgency (k=0.287; p<0.0001) (Table 3)
- For patients diagnosed with metastatic or nonmetastatic disease, 62% and 50%, respectively, self-reported hematuria at diagnosis, 48% and 40%, respectively, self-reported urinary dysuria, and 49% and 36%, respectively, self-reported frequent need to urinate (Figure 2)

Table 1. Patient demographics

| | All patients (n=442) |
|-----------------------------|----------------------|
| Age, years | |
| Mean (SD) | 68.8 (8.3) |
| Sex, n (%) | |
| Male | 300 (68) |
| Female | 141 (32) |
| Intersex | 1 (<1) |
| Smoking status, n (%) | |
| Current smoker | 99 (22) |
| Ex-smoker | 280 (63) |
| Never smoked | 55 (12) |
| Unknown | 8 (2) |
| Employment status, n (%) | |
| Retired | 315 (71) |
| On long-term sick leave | 48 (11) |
| Working (full or part time) | 30 (7) |
| Homemaker | 23 (5) |
| Unemployed | 19 (4) |
| Unknown | 7 (2) |
| Caregiver status, n (%) | |
| Has a caregiver | 272 (62) |
| Does not have a caregiver | 114 (26) |
| Unknown | 56 (13) |

METHODS

- Data were drawn from the Adelphi Real World (ARW) mUC Disease Specific Programme (DSP), a cross-sectional survey of medical oncologists/urologists and their patients with mUC in France, Germany, Italy, Spain, and the UK, from December 2023 to July 2024
- The DSP methodology has been previously published and validated⁵⁻⁷
- Physicians were eligible for inclusion if they were personally responsible for the treatment and management of patients with mUC, spent at least half their time in patient management, saw a minimum of 4 patients with bladder cancer per month, and accepted all survey rules and requirements
- Patients were eligible for inclusion if they were aged ≥ 18 years and had a confirmed diagnosis of mUC

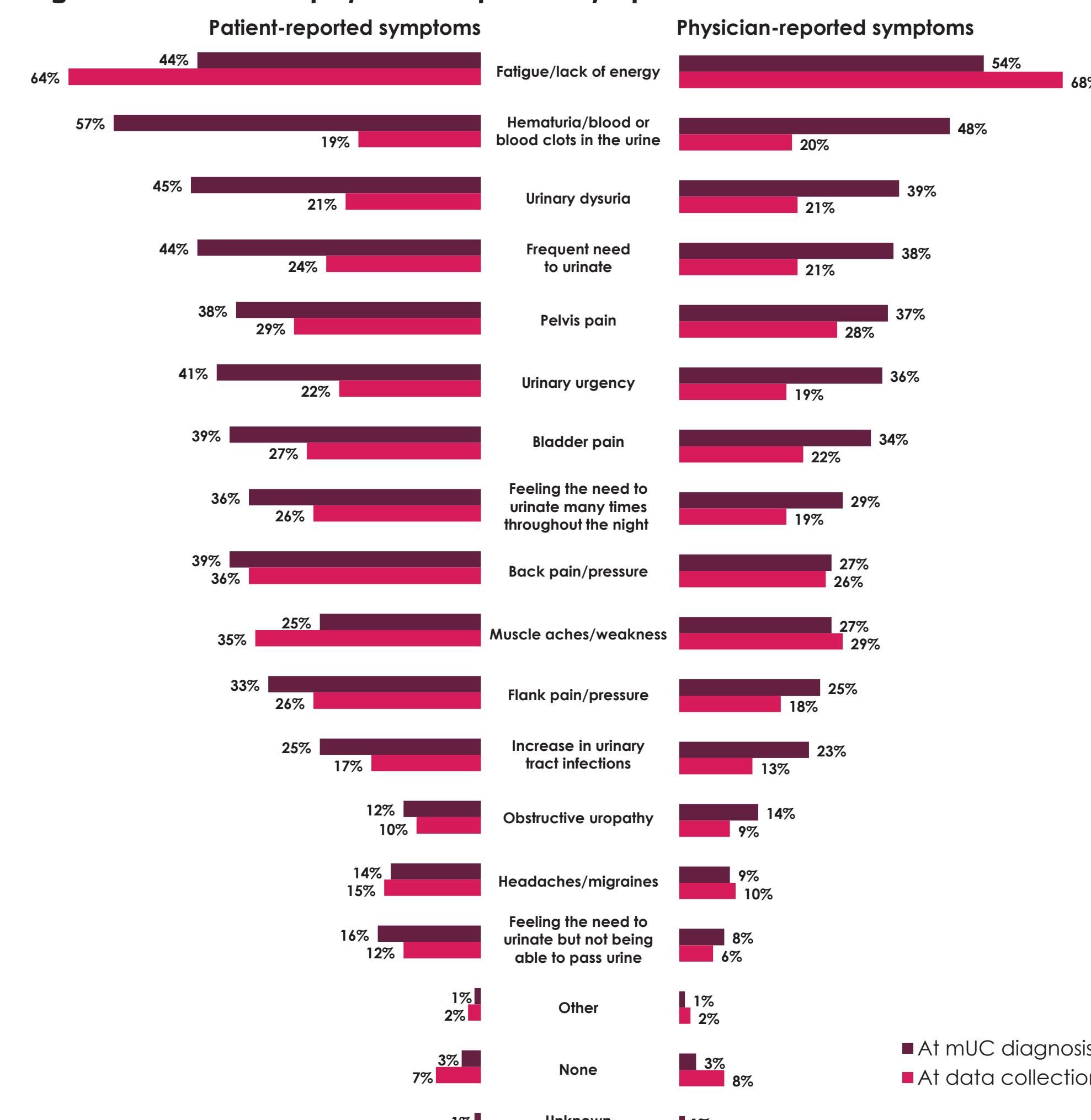
- Physicians completed patient record forms (PRFs), which reported patient demographics and clinical characteristics including mUC symptoms
- Patients for whom their physician completed a PRF were invited to voluntarily complete a patient self-completion form (PSC), which captured the patient's perspective of their disease and treatment, including symptoms experienced
- Patients were eligible for inclusion in the analysis if they had a matched PRF and PSC and had reported their symptoms at the time of data collection in the PSC
- Agreement between patient- and physician-reported symptoms at data collection was measured using Cohen's κ coefficient, with the level of agreement categorized as perfect ($\kappa > 0.8$ to ≤ 1.0), good ($\kappa > 0.6$ to ≤ 0.8), moderate ($\kappa > 0.4$ to ≤ 0.6), fair ($\kappa > 0.2$ to ≤ 0.4), or poor ($\kappa > 0.0$ to ≤ 0.2)

Table 2. Tumor location and disease stage

| Tumor location at initial UC diagnosis, n (%) | All patients (n=442) |
|---|----------------------|
| Bladder | 385 (87) |
| Ureter | 25 (6) |
| Renal pelvis | 25 (6) |
| Urethra | 5 (1) |
| Other | 2 (<1) |
| Disease stage at initial diagnosis for those with a bladder tumor, n (%) | n=385 |
| 0a or 0is | 7 (2) |
| I | 19 (5) |
| II | 26 (7) |
| IIIA | 25 (6) |
| IIIB | 18 (5) |
| IVA (M0) | 52 (14) |
| IVB (M1) | 119 (31) |
| IVA (M1) | 116 (30) |
| Unknown nonmetastatic UC stage | 2 (1) |
| Unknown metastatic UC stage | 1 (<1) |

UC, urothelial carcinoma.

Figure 1. Patient and physician-reported symptoms

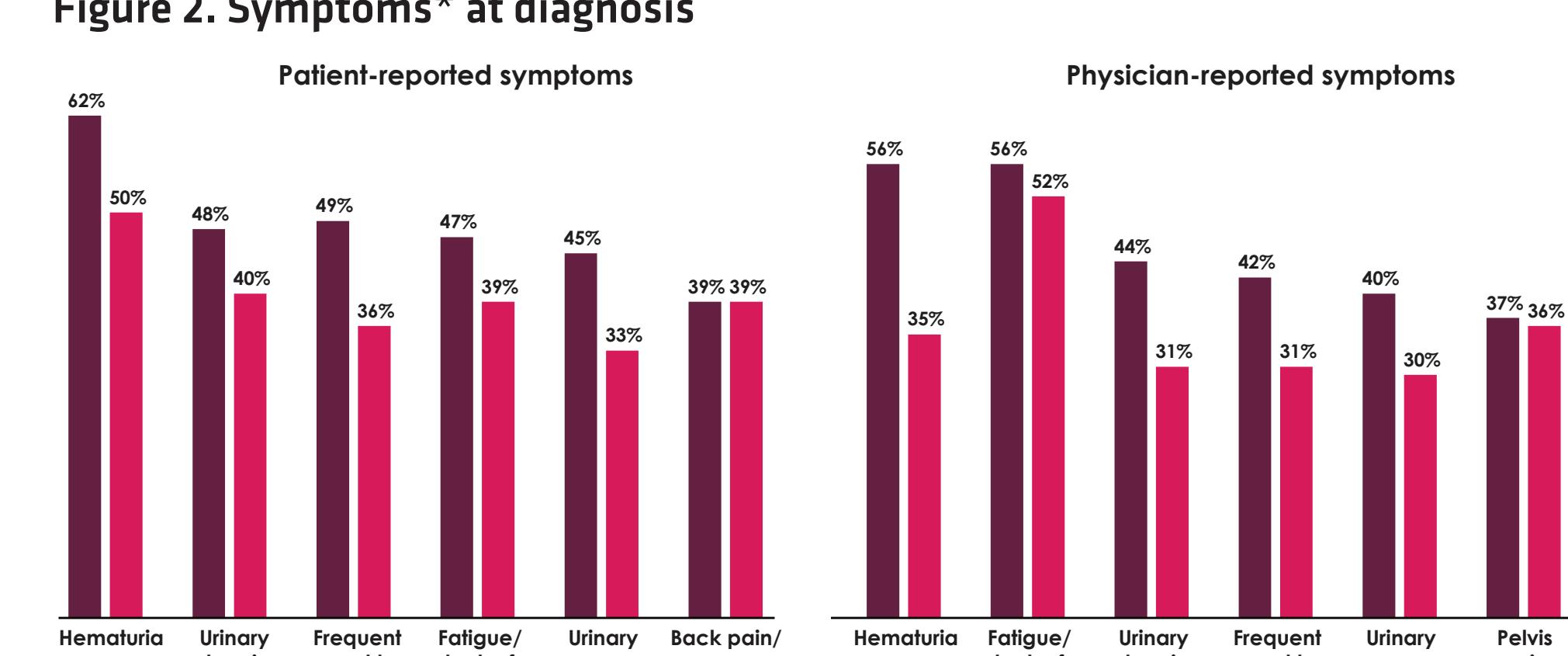


mUC, metastatic urothelial carcinoma.

Table 3. Patient- and physician-reported symptom concordance at data collection

| Symptom | All patients (n=442) | | |
|--|----------------------|-------------------------|--------------------|
| | κ Value | Percentage of agreement | Level of agreement |
| Obstructive uropathy | 0.561 | 92.5 | Moderate |
| Feeling the need to urinate many times throughout the night | 0.504 | 82.6 | Moderate |
| Pelvis pain | 0.487 | 79.2 | Moderate |
| Increase in urinary tract infections | 0.486 | 86.7 | Moderate |
| Bladder pain | 0.466 | 80.1 | Moderate |
| Fatigue/lack of energy | 0.460 | 75.6 | Moderate |
| Flank pain/pain | 0.455 | 81.0 | Moderate |
| Muscle aches/weakness | 0.454 | 76.2 | Moderate |
| Hematuria/blood or blood clots in the urine | 0.423 | 81.9 | Moderate |
| Back pain/pain | 0.413 | 74.4 | Moderate |
| Urinary dysuria | 0.401 | 80.1 | Moderate |
| Frequent need to urinate | 0.393 | 78.7 | Fair |
| Headaches/migraines | 0.366 | 86.2 | Fair |
| Feeling the need to urinate but not being able to pass urine | 0.288 | 88.0 | Fair |
| Urinary urgency | 0.287 | 76.5 | Fair |

Figure 2. Symptoms* at diagnosis



*Top 5 symptoms at the time of diagnosis are presented for both patients diagnosed with metastatic disease or nonmetastatic disease.

LIMITATIONS

- Physicians were asked to provide data on consecutively consulting patients who met the eligibility criteria; thus, this study does not reflect a true random sample as patients who consulted more frequently were more likely to be included
- Physicians and patients were requested to capture patient information retrospectively in the PRF and PSC, which may have introduced recall bias—a common limitation of survey data. However, physicians did have the ability to refer to the patients' medical records when completing the PRF, thus minimizing the possibility of recall bias. Moreover, most questions in the PSC have a limited recall period to further minimize the risk of recall bias
- Study data were self-reported by physicians and patients. No independent verification was possible due to the nature of the ARW mUC DSP methodology

GET POSTER PDF

Copies of this poster obtained through this Quick Response (QR) code are for personal use only and may not be reproduced without permission from ISPOR Europe 2025 and the corresponding author of this poster.

Correspondence: Mairead Kearney, mairead.kearney@merckgroup.com

