Survey of Challenges in Access to Diagnostics and Treatment for Neuroendocrine Tumor (NET) Patients (SCAN) – USA and Canada vs Global Diagnosis of NETs

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INTRODUCTION

- Neuroendocrine tumors (NETs) are rare and complex neoplasms, affecting multiple organs, but most commonly the gastrointestinal tract.[1]
- NETs incidence and prevalence is increasing globally, making it one of the fastest growing classes of cancer.[1]
- The International Neuroendocrine Cancer Alliance (INCA) consists of 26 patient advocacy and research groups and supports NET patients and their families by advocating on their behalf to improve diagnosis, care and research.

OBJECTIVES

- This survey (SCAN) aims to measure the global readiness to provide access to diagnostics and treatments for NET patients in terms of:

Awareness	Availability	Quality	Affordability

- This analysis focused on responses from NET patients and healthcare professionals on the early diagnosis of NETs in USA and Canada vs the situation globally.

METHODS

- During Sept-Nov 2019, NET patients and healthcare professionals (HCP) completed an online survey.
- The survey was disseminated via social media and NET patient groups' and medical societies' networks.
- The survey was available in 14 languages:
  - Arabic, Bulgarian, English, German, Dutch/Flemish, French, Japanese, Hindi, Italian, Mandarin (Chinese), Portuguese, Russian, Spanish, and Swahili.
- On average, NET patients took 20 minutes and HCPs 11 minutes to complete the questionnaire.

PARTICIPANT CHARACTERISTICS

- 2359 NET patients and 436 HCPs from 68 countries responded
- Of the NET patients 22% (511/2359) were from the United States (US) and 9% (208/2359) were from Canada (CA).
- Primary NETs were most often gastroenteropancreatic (GEP) NETs, slightly less in US and more in CA than globally (Global: 71% [1670/2359]; US: 63% [323/511]; CA: 74% [154/208]; p<0.0001, Chi-squared, Figure 1).

Figure 1: Primary NET type

CA: Canada; GEP: Gastroenteropancreatic; NET: Neuroendocrine tumor; US: United States
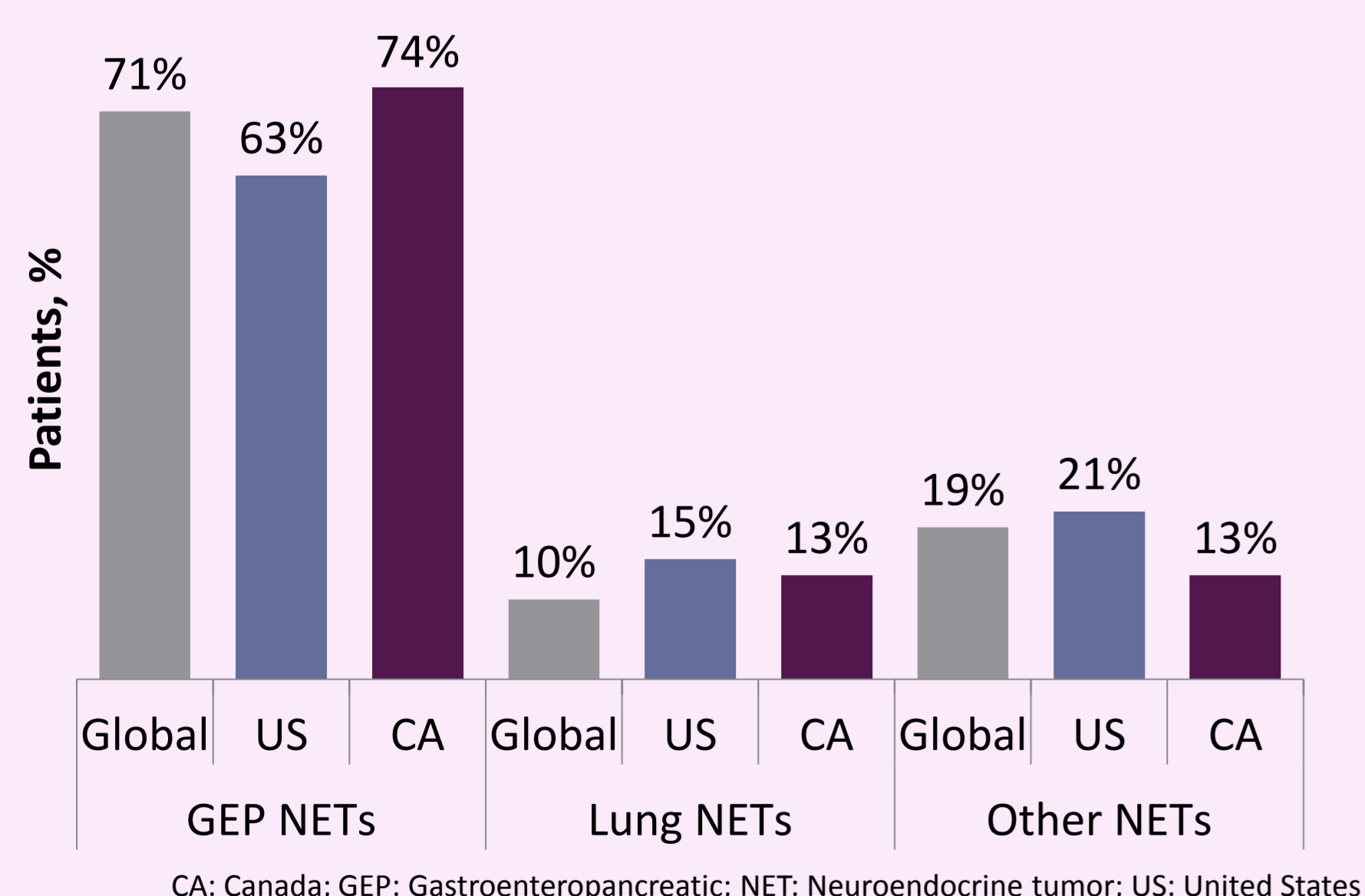
- Mean patient age at the time of diagnosis globally was 51 years; 53 years in both the US and CA.
- Patients globally had a NET diagnosis in a mean of 5 years; 6 years in US and CA.

RESULTS

Misdiagnosis

- Almost half of patients were initially misdiagnosed with other conditions at least once (Global: 44% [1043/2359]), US: 48% [245/511]; CA 46% [96/208], Figure 2).
- Mean time to correct diagnosis was 5 years globally, 6 years in US and 7 years in CA (Figure 2).
- Almost half of patients globally, and a significantly higher proportion in US and CA, were diagnosed with stage IV NETs or had metastases at time of diagnosis (Global: 46% [1077/2359]; US: 52% [266/511]; CA: 52% [109/208]; p<0.0001).

Figure 2: Mean time to receive NET diagnosis and proportion of misdiagnosis
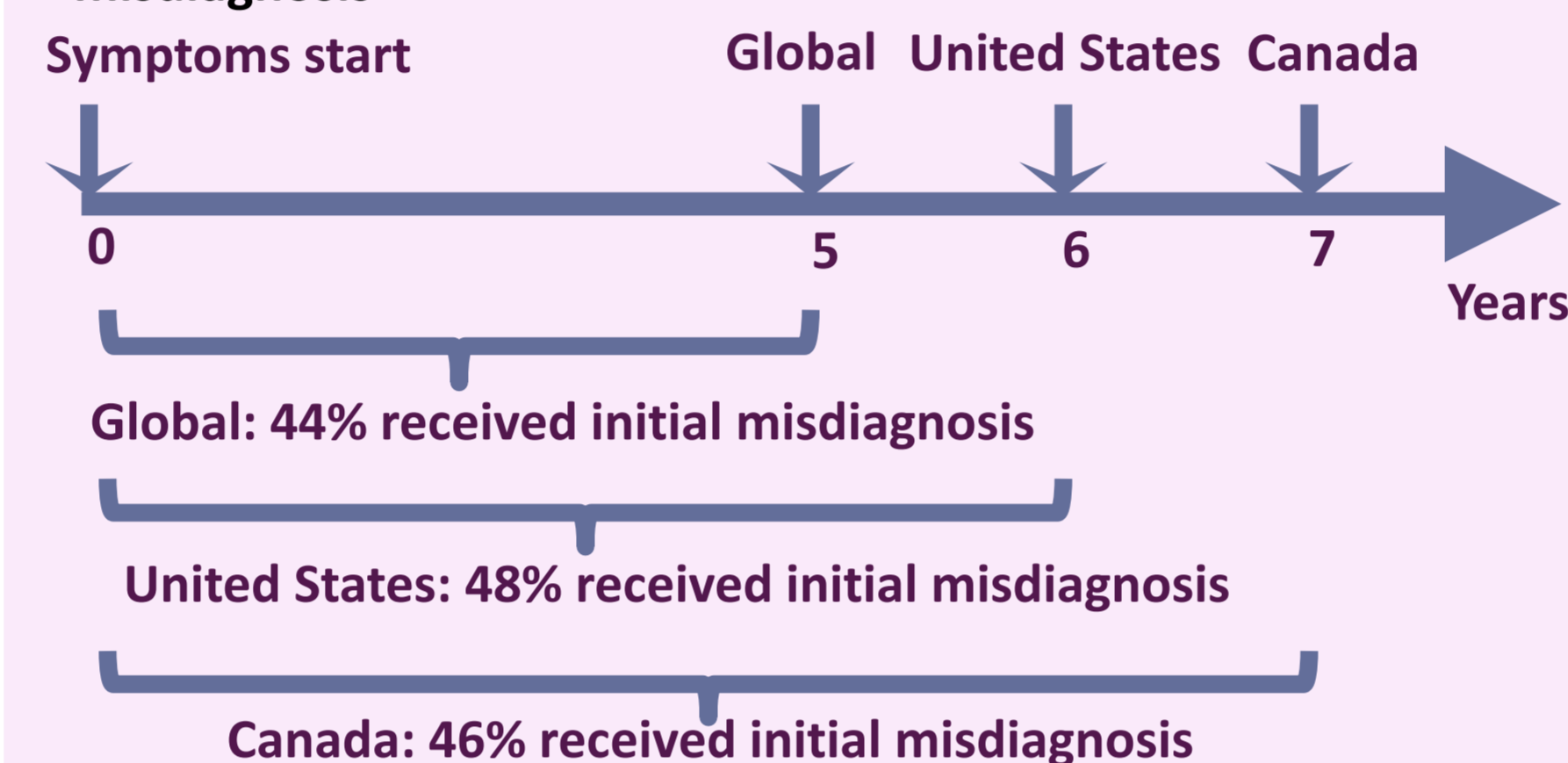

Diagnostic Tools

- The diagnostic tools that most often led to correct diagnosis were biopsy (Global: 59% [1392/2359]; US: 55% [281/511]; CA: 57% [119/208]) and CT scan, significantly higher in US and particularly in CA compared to globally (Global: 46% [1060/2359], US: 54%[278/511], CA: 63% [131/208]; p<0.0001, Figure 3).

Figure 3: Diagnostic tool leading to diagnosis

CA: Canada; US: United States
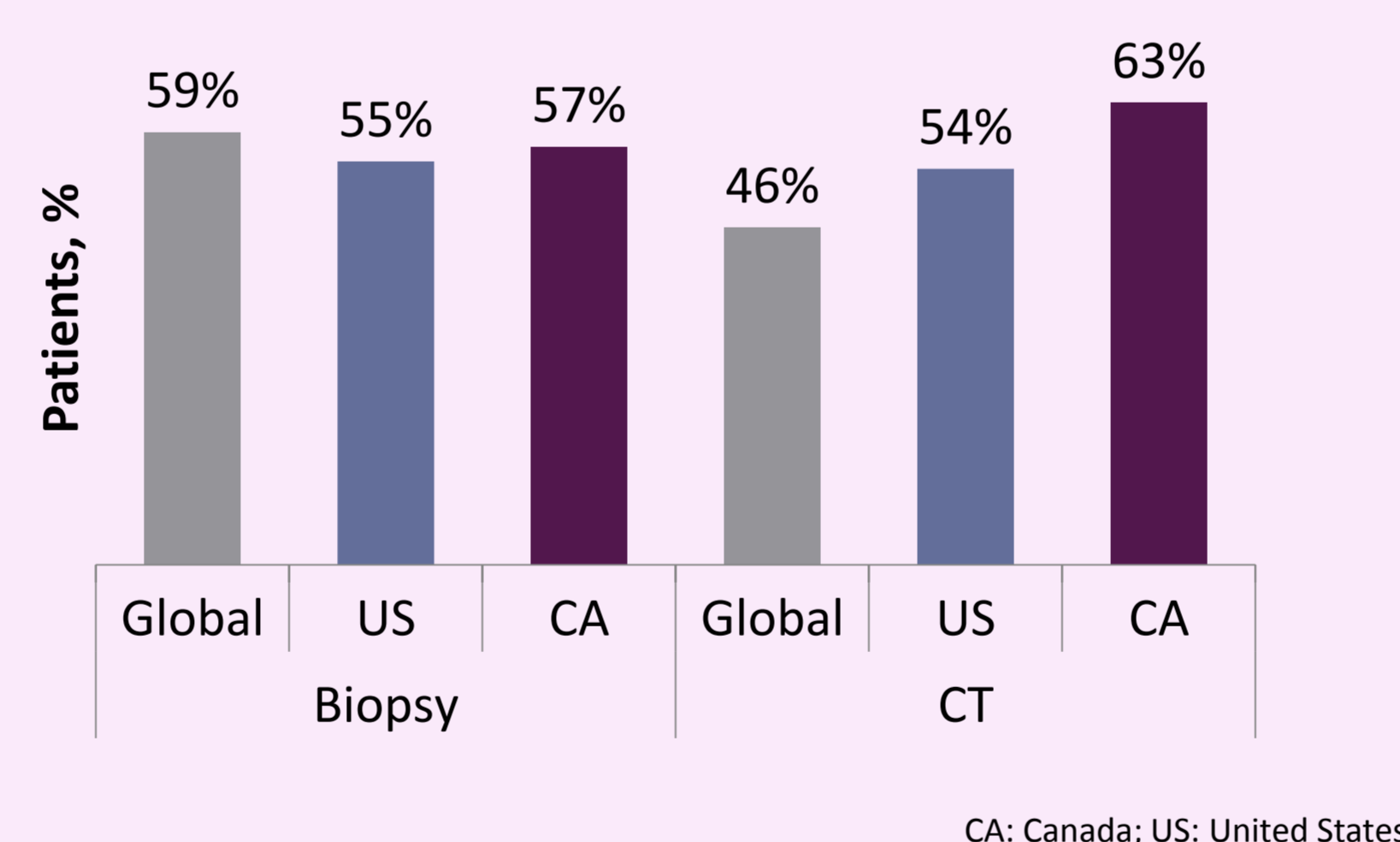
- In Canada more conventional imaging tools were used for diagnostics *versus* the US and globally (Figure 4):
  - MRI (Global: 23% [543/2359], US: 25% [128/511], CA: 31% [65/208]; p<0.0001)
  - Octreotide Scan (Global: 15% [354/2359], US: 13% [66/511], CA: 30% [62/208]; p<0.0001)
  - Ultrasound (Global: 17% [401/2359], US: 16%[82/511], CA: 26% [54/208]; p<0.0001)
- Specialized Gallium 68 DOTANOC PET CT was of significantly lower usage both in US and CA *versus* globally (Global: 18% [425/2359], US: 13% [66/511], CA: 4% [8/208]; p<0.0001, Figure 4).

Figure 4: Usage of conventional and specialised diagnostic tools

CA: Canada; US: United States; 68-Ga: Gallium 68 DOTANOC PET CT
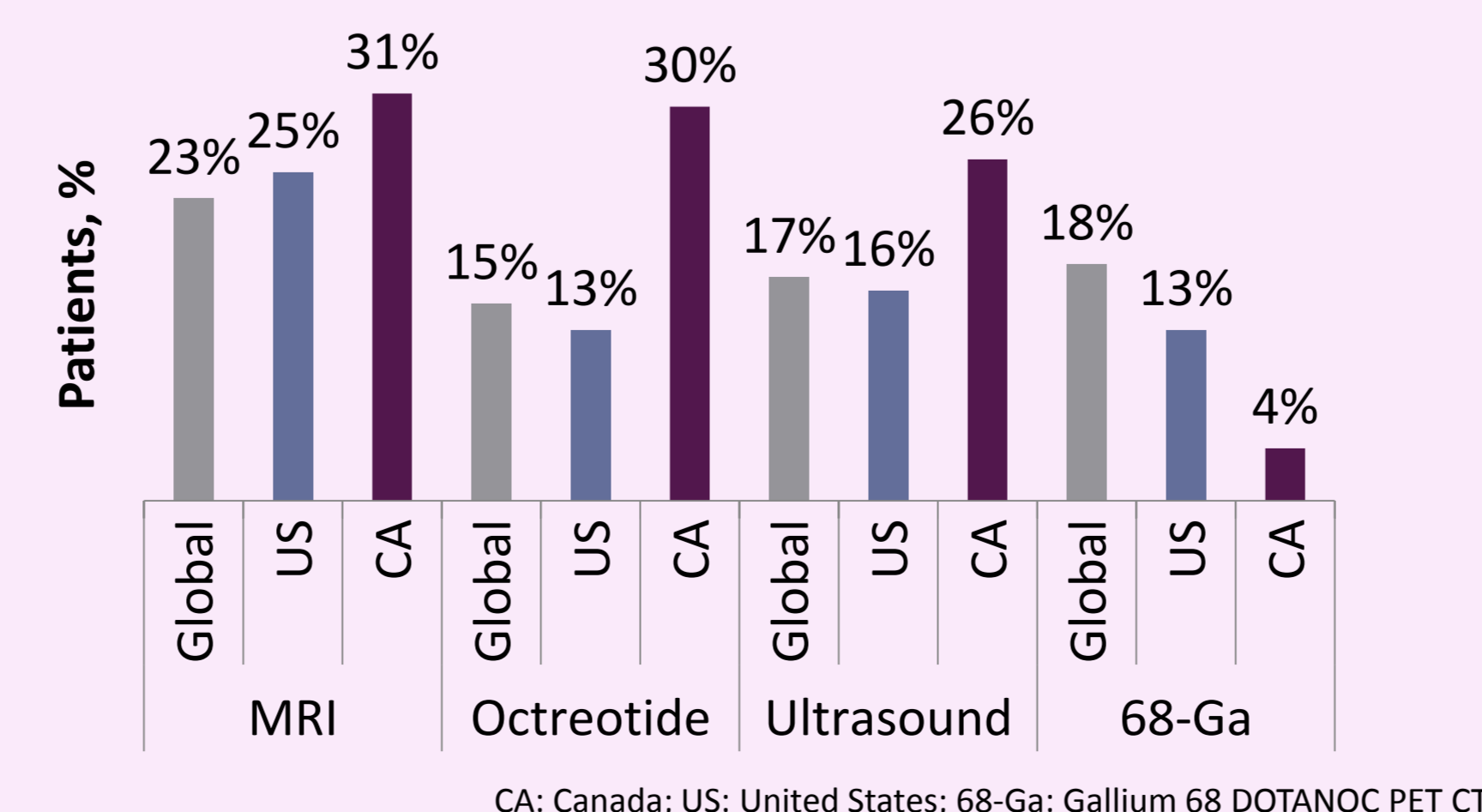
RESULTS [cont.]

Issues and Recommendations

- The top three issues surrounding NETs care in the US and CA were:
  - "lack of experts to provide first and second opinion" (US: 31% [159/511]; CA: 29% [60/208])
  - "no multidisciplinary team at all" (US: 30% [153/511]; CA: 26% [54/208])
  - "lack of reliable information about your NETs" (US: 26% [133/511]; CA: 26% [54/208]).
- The most common recommendations to improve NET diagnosis and management in the US and CA were:
  - "more healthcare professionals knowledgeable in NETs" (US: 78% [399/511]; CA: 61% [127/208])
  - "better access to NET experts/specialist centers" (US: 62% [317/511]; CA: 56% [117/208]).

CONCLUSIONS

- **SCAN represents the largest global compendium of data about NETs extant.**
- **Misdiagnosis is a global challenge for NET patients.**
- **Late diagnostic staging of NETs, significantly pronounced in US and CA, may influence therapies and shorten life expectancy.**
- **More recent diagnostic tools need to be applied both in US and CA for early detection and complete staging.**
- **This survey further contributes to positioning NET research on an equal footing with other cancers of similar prevalence.**

REFERENCES

1. Dasari A, Shen C, Halperin D, *et al.* JAMA Oncol 2017;3:1335-42.

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