

NET Treatments and Follow-up Disease Management Comparative Perspective (US and Canada vs. Global)



Ron Hollander¹, Teodora Kolarova², Mark McDonnell³, Catherine Bouvier⁴, Marianne Pavel⁵, Harjit Singh⁶, James R. Howe⁷, Dermot O'Toole⁸, Jie Chen⁹, Simone Leyden¹⁰, Elyse Gellerman¹¹, Sugandha Dureja¹², Christine Rodien-Louw¹³, Dirk Van Genechten¹⁴, Simron Singh¹⁵

¹INCA, Boston, US, ²INCA, Boston, US, ³NET Patient Network, Dublin, Ireland, ⁴Neuroendocrine Cancer UK, Leamington Spa, UK, ⁵Department of Endocrinology, Friedrich Alexander University Erlangen-Nuernberg, Erlangen, Germany, ⁶Prince Court Medical Centre 39, Jalan Kia Peng, Kuala Lumpur, Malaysia, ⁷University of Iowa Carver College of Medicine, Iowa City, Iowa, USA, ⁸National Centre for Neuroendocrine Tumours, St. Vincent's University and Department of Clinical Medicine, St. James Hospital and Trinity College, Dublin, Ireland, ⁹The First Affiliated Hospital, Sun Yat-sen University, Guangdong, China, ¹⁰NeuroEndocrine Cancer Australia, Blairgowrie, Victoria, Australia, ¹¹NET Research Foundation, Boston, Massachusetts, USA, ¹²CNETS India, New Delhi, India, ¹³APTED, Lyon, France, ¹⁴vzw NET & MEN Kanker Belgium, Kortrijk, Belgium, ¹⁵Sunnybrook Odette Cancer Centre, University of Toronto, Toronto, Ontario, Canada

INTRODUCTION

- Neuroendocrine tumors (NETs) are rare and complex neoplasms, affecting multiple organs, but most commonly the gastrointestinal tract.¹
- Globally, NET incidence and prevalence are increasing, making it one of the fastest growing classes of cancer.¹
- The International Neuroendocrine Cancer Alliance (INCA) consists of 27 patient advocacy and research groups and supports NET patients and their families by advocating on their behalf to improve diagnosis, care and research.

OBJECTIVE

- 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

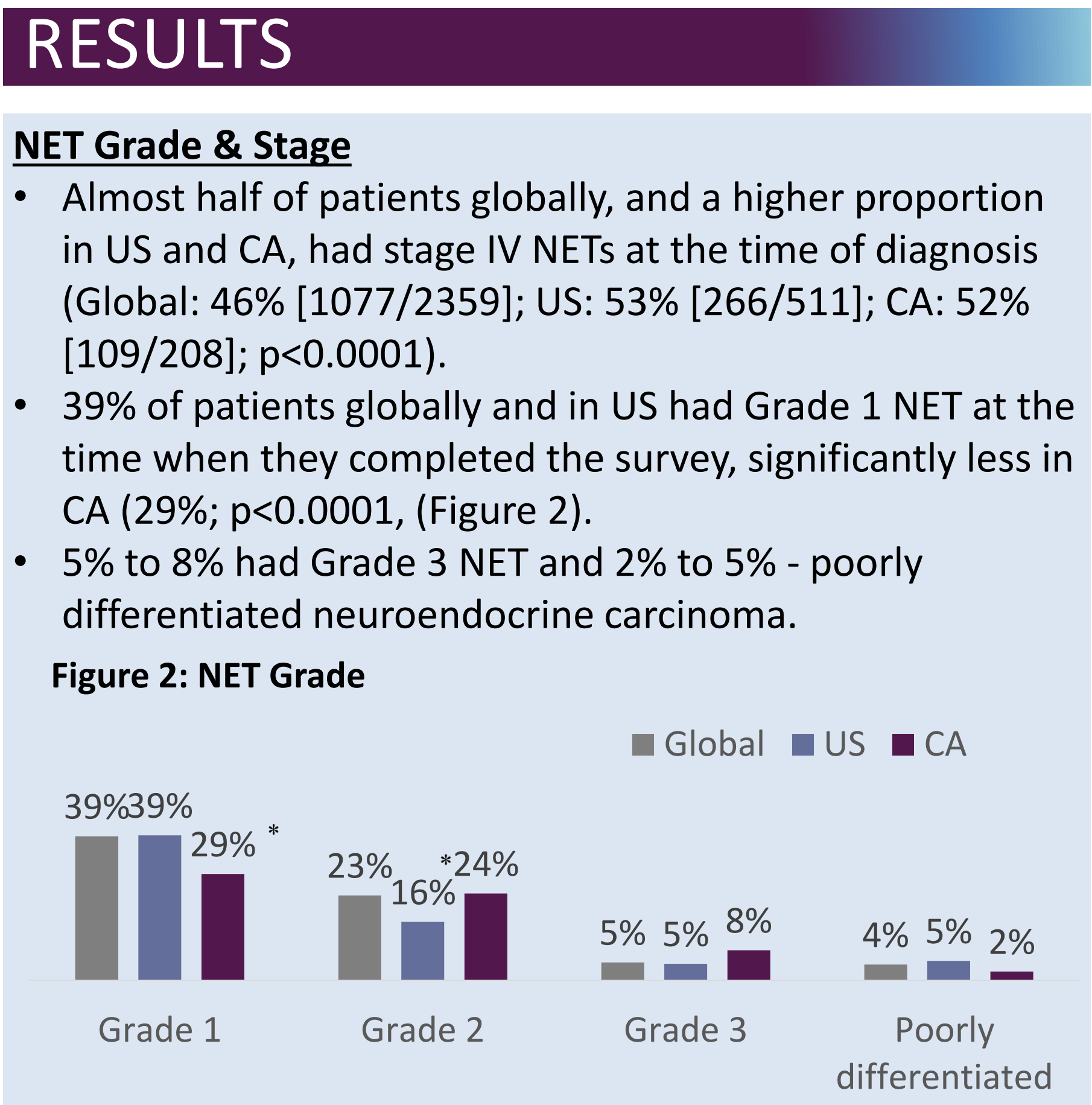
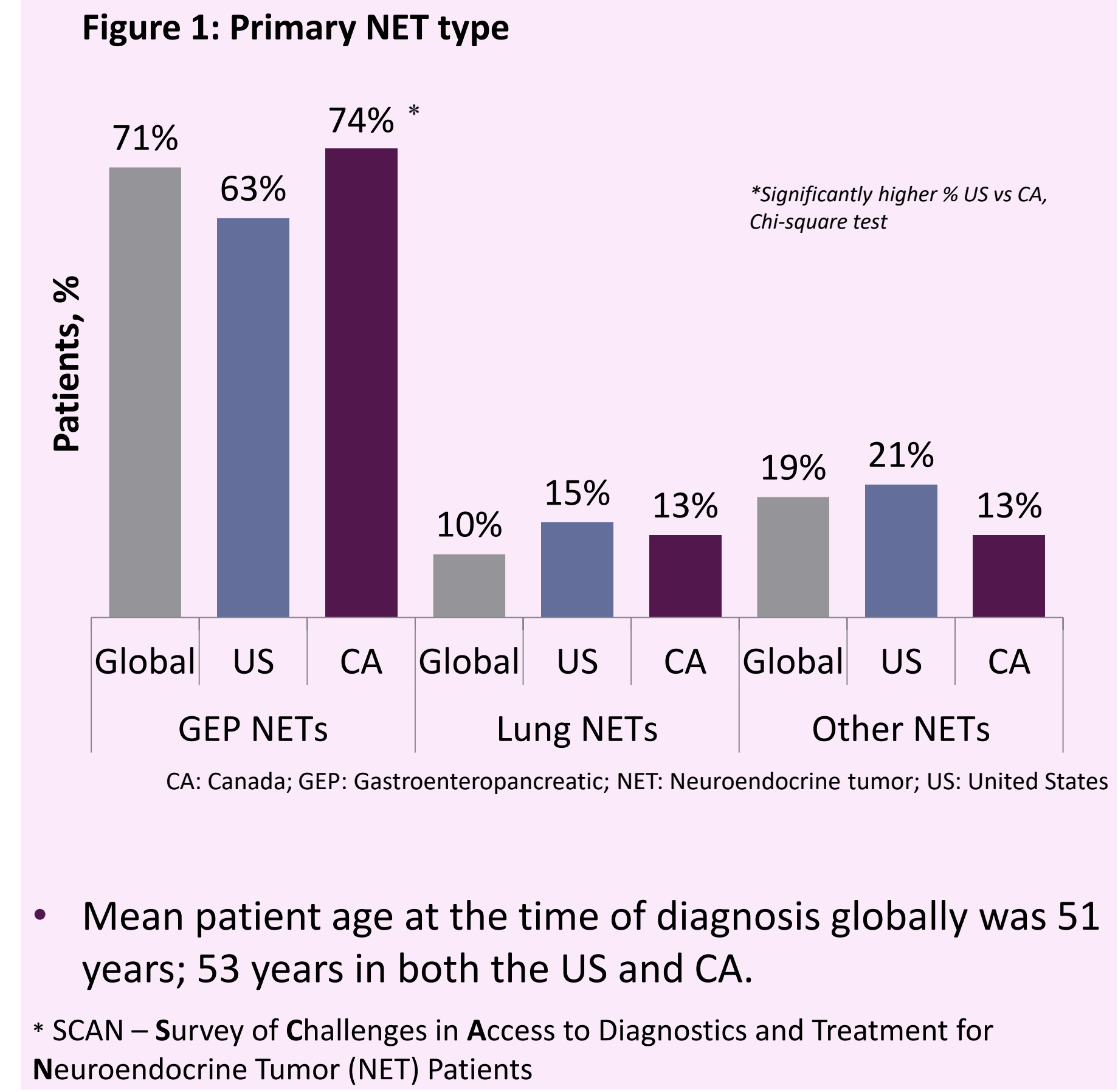
- This analysis focused on NET treatment and follow-up disease management in USA (US) and Canada (CA) vs. the situation globally (Global).

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.

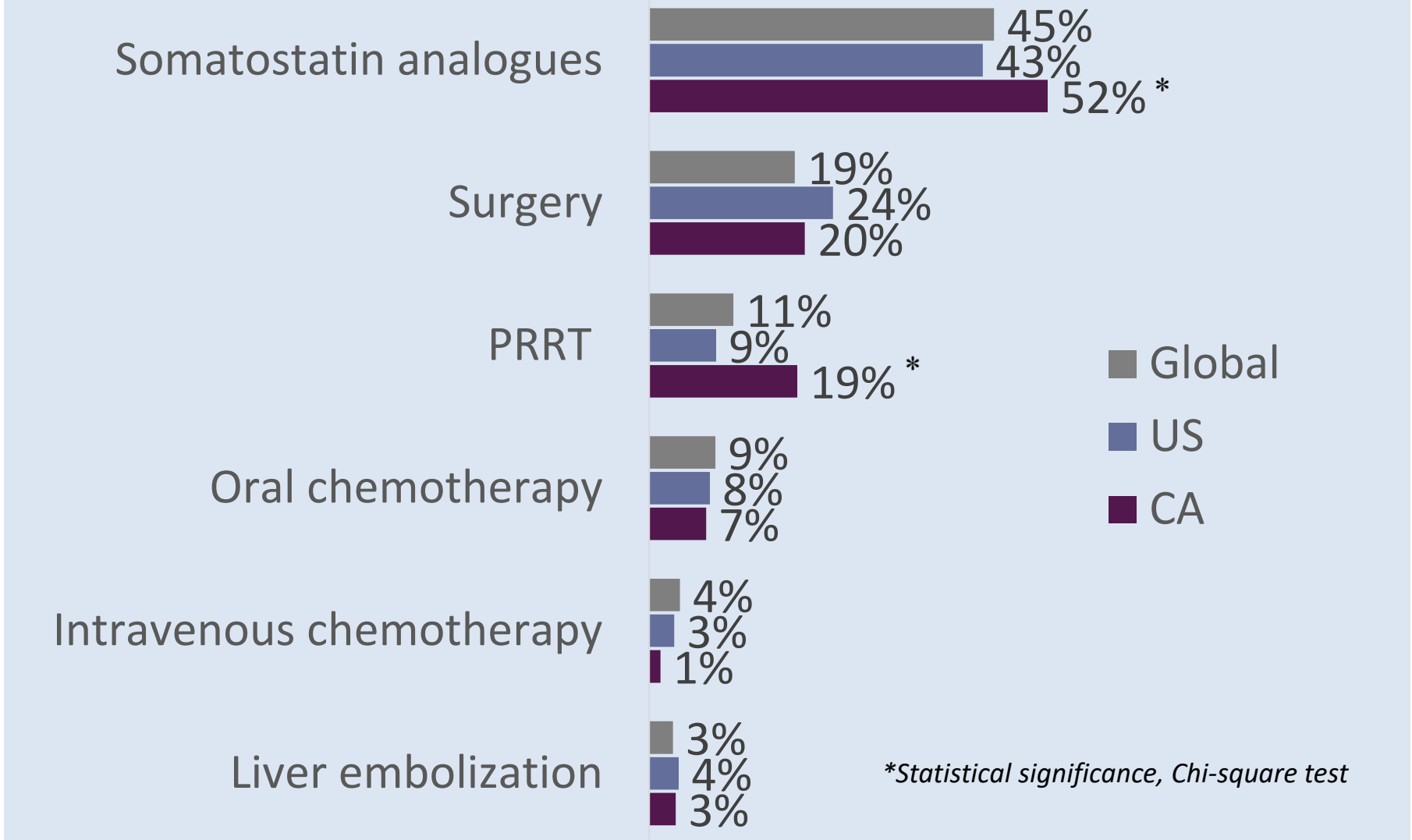
PARTICIPANT CHARACTERISTICS

- 2359 NET patients and 436 HCPs from 68 countries responded
- 22% (511/2359) of NET patient respondents 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).

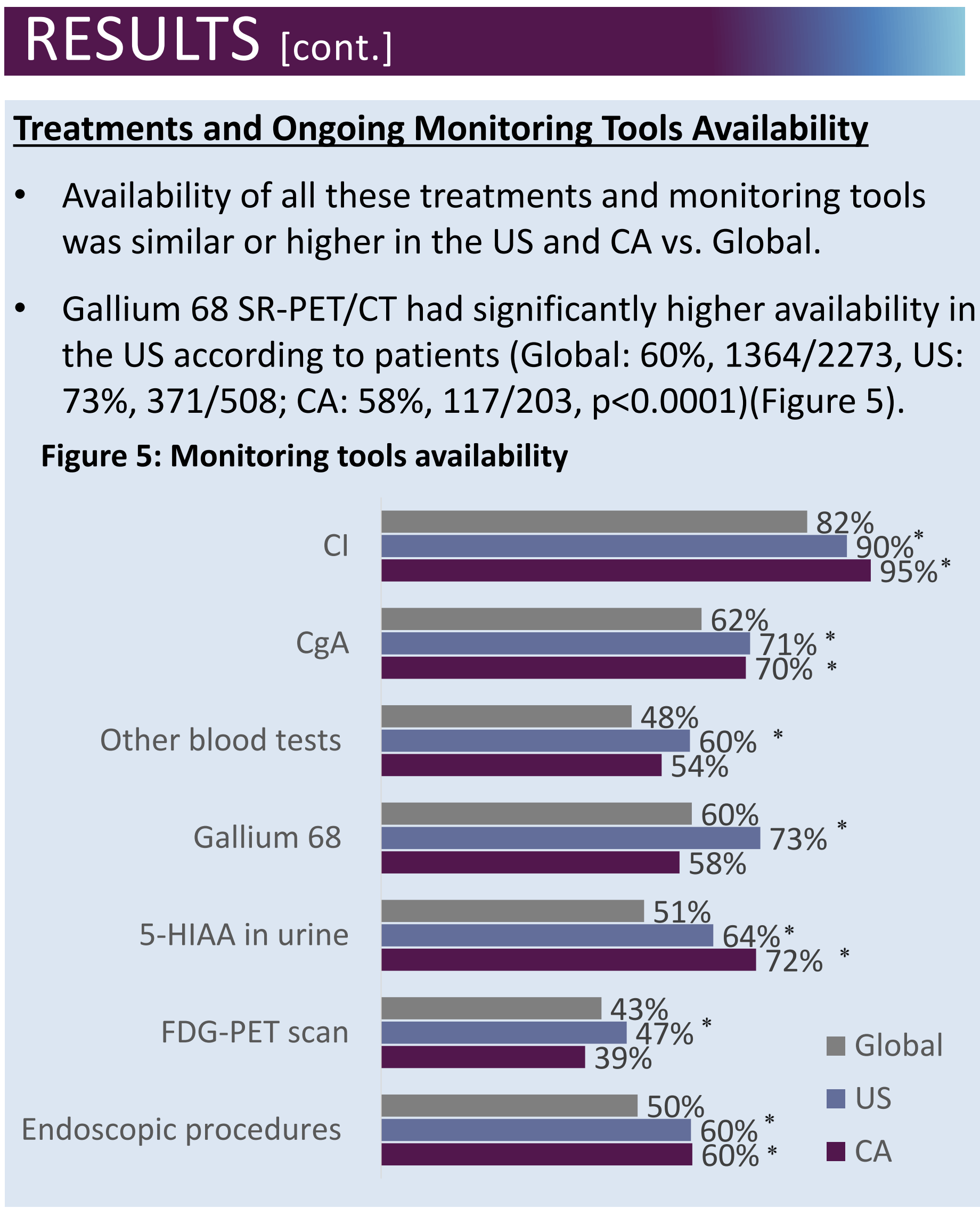
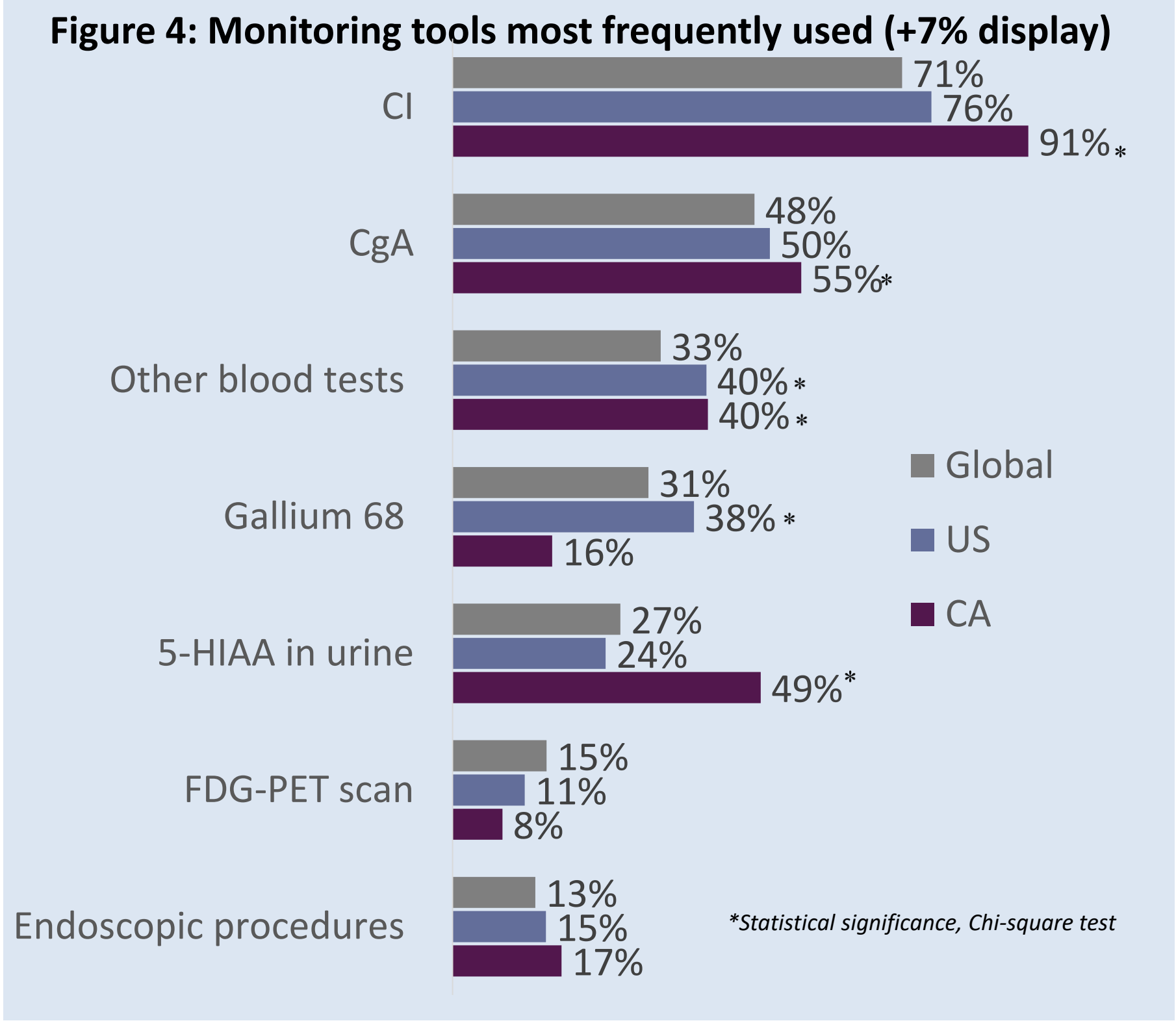


Treatment Tools Used

- Almost half of NET patients on treatment used somatostatin analogues (SSA; Global: 45%, 1022/2274, US: 44%, 214/492; CA: 52%, 105/202) (Figure 3)
- About one-fifth underwent surgery (Global: 19%, 432/2274, US: 24%, 118/492; CA: 20%, 41/202)
- About 10% received PRRT, more in CA (Global: 11%, 250/2274, US: 9%, 43/492; CA 19%, 39/202, p<0.0001).



- More patients in the US and especially in CA were monitored by conventional imaging (CI), e.g. CT, MRI, ultrasound (Global: 71%, 1617/2273, US: 76%, 100/508; CA: 91%, 185/203);
- Other blood tests were administered more frequently in the US and CA vs. Global (Global: 33%, 749/2273, US: 40%, 204/508; CA: 40%, 82/203).



CONCLUSIONS

- SCAN represents the biggest global compendium of data about NETs to date.
- There is a divergence between the treatment and follow-up approaches used globally, in CA and the US.
- Data clearly demonstrate the differences in providing NET care, both globally and within advanced economies such as US and CA.
- Follow-up disease management strategies vary significantly around the world.
- A consensus on the optimal standard follow-up for NETs is still lacking.

REFERENCES

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

ACKNOWLEDGEMENTS

INCA would like to thank all its members as well as its partners: ENETS (European Neuroendocrine Tumor Society), NANETS (North American Neuroendocrine Tumor Society), APNETS (Asia-Pacific Neuroendocrine Society), CommNETs (Commonwealth Neuroendocrine Tumor Group), JNETS (Japan Neuroendocrine Tumor Society), CNETS (Chinese Neuroendocrine Tumor Society), UICC (Union for International Cancer Control), EURORDIS (European Organisation for Rare Diseases), NORD (National Organization for Rare Disorders) and E.C.O. (European Cancer Organisation) and many others for their instrumental support of this global effort.

FUNDING AND DISCLOSURE

- This study was sponsored by Ipsen, ITM and Novartis.
- The lead author has nothing to declare.