

---

# **What Patients Expect from their MS Nurse: Canadian Survey Results**

Colleen Harris MN NP MSCN  
University of Calgary MS Clinic

# Objective

- At the conclusion of this session the participant will be able to:
  - discuss what roles of Canadian MS Nurses are valued highly by patients

# Nursing Challenges in Canada

- Canadian nurses have enjoyed a close collaboration through the structure of the “Network of MS Centers”
- We often connect at meetings and by email to develop best practices and share frustrations
- Growing patient care demands and complex new treatments were voiced as challenges to resources and time
- Nurses were concerned about gaps in services and wanted to know how well we were doing in meeting patient expectations

# Nursing Collaborative Group

- **Colleen Harris**, MN NP MSCN, Foothills Medical Centre, Calgary, Alberta
- **Bonnie Blain**, RN, MSCN, Central Alberta MS Clinic, Red Deer, Alberta
- **Janet Brown**, RN, MSCN, MS Clinic–Eastern Health, St. John's, Newfoundland-Labrador
- **Peggy Cook**, RN, BN, Saint John Regional Hospital, Saint John, New Brunswick
- **Josée Poirier**, BSc, MSCN, Hôpital Notre-Dame (CHUM), Montreal, Quebec
- **Sheryl Clarke**, RN, BScN, St. Michael's Hospital, Toronto, Ontario
- **Shirley MacGowan**, RN, MSCN, Saskatoon City Hospital, Saskatoon, Saskatchewan
- **Lynn McEwan**, BSN, NP, MSCN, London Health Sciences Centre, London, Ontario

# Looked at Previous Work in this Area

- Burke T., Dishon S., McEwan L., & Smirtka J. (2011). The evolving role of the MS nurse. An international perspective. *Int J MS Care* 13, 105-112.
  - Described challenges to the future of MS Nursing related to therapeutics
- Galushko M., et al (2014). Unmet needs of patients feeling severely affected by MS in Germany: A qualitative study. *Journal of Palliative Medicine*, 17, 3, 274-281
  - Themes of unmet family support, challenges with physician/patient relationship, inadequate health care services including palliative care
- Rieckmann P., et al (2015). Achieving patient engagement in MS: A perspective from the MS in the 21<sup>st</sup> Century Steering Group. *MS and Related Disorders*, 4, 2012-218
  - Discussed strategies for better patient and family engagement in care of the future

# Approached MSology



- MSology is an open-access news/information website based in Canada for patients with MS; launched in 2012
- Approx. 40,000 visitors/year worldwide
  - Most visitors from English-speaking countries with high MS prevalence: Canada, USA, UK
  - Visitor demographics are representative of MS prevalence and age group
- Has worked with the Canadian MS nursing community since launch to develop content
  - Patient information booklets
  - Infographics
  - Radio programs (MS Radio) of roundtable discussions (MS symptoms, self-management, etc.)

# MSology MS Nursing Survey Project

## **Project Purpose:**

To use patient survey(s) on MSology to stratify the most important nursing roles by category (e.g. providing specific healthcare services, education, safety monitoring, side effect management, lifestyle advice, psychosocial support, etc.) and by task as perceived by patients.

## Survey:

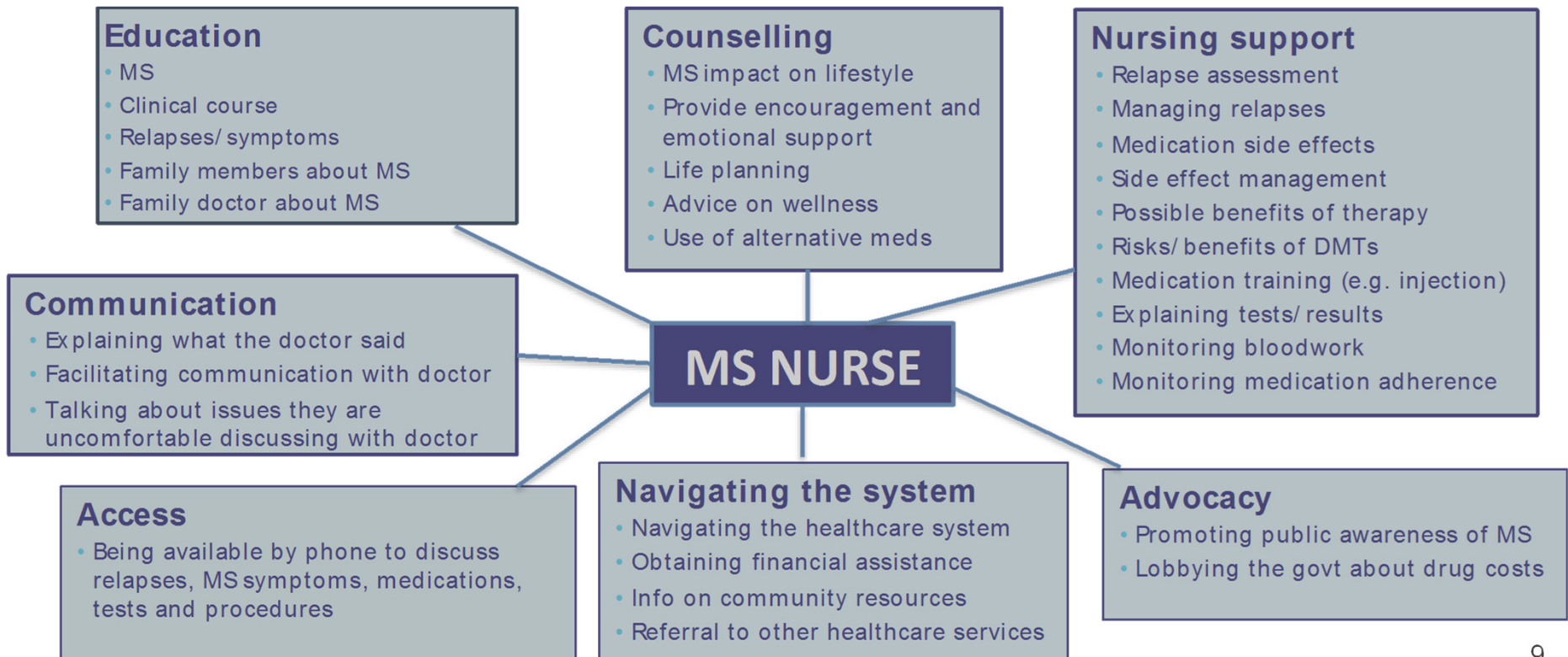
# What Do Patients Expect from their MS Nurse?

Canadian MS Nursing group developed a preliminary list of questions (max. 20). Examples of areas that were surveyed:

- Demographics
- Current expectations of their MS nurse
- MS nursing-specific roles (vs. neurologist, GP, other HCPs, patient support program nurses)
- Responses:
  - Multiple choice, Likert scale (5 responses); write-in questions



# Surveying the Many Faces of MS Nursing



# MSology Web Platform - Survey

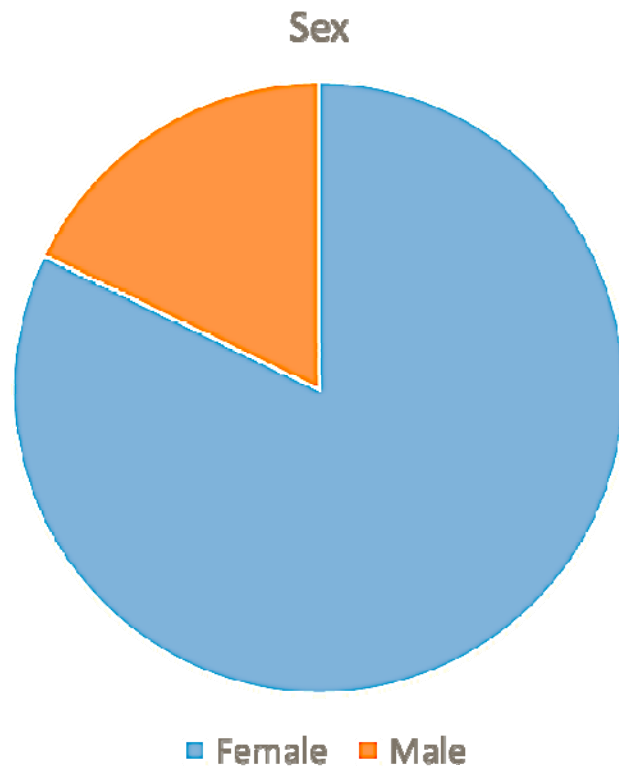
- Survey was posted on MSology ([www.msology.com](http://www.msology.com)) in the period June to September 2016
- Posted in English and in French
- Responses were anonymous
- Survey was housed on MSology website and promoted on MSology social media accounts (Facebook, Twitter, Pinterest)

# Results

- Total number of respondents: 248
  - Non-Canadian respondents excluded from analysis (n=22)
  - Analysed n=226 (English, n=187; French, n=39)

# Q1: I am...

## DEMOGRAPHICS



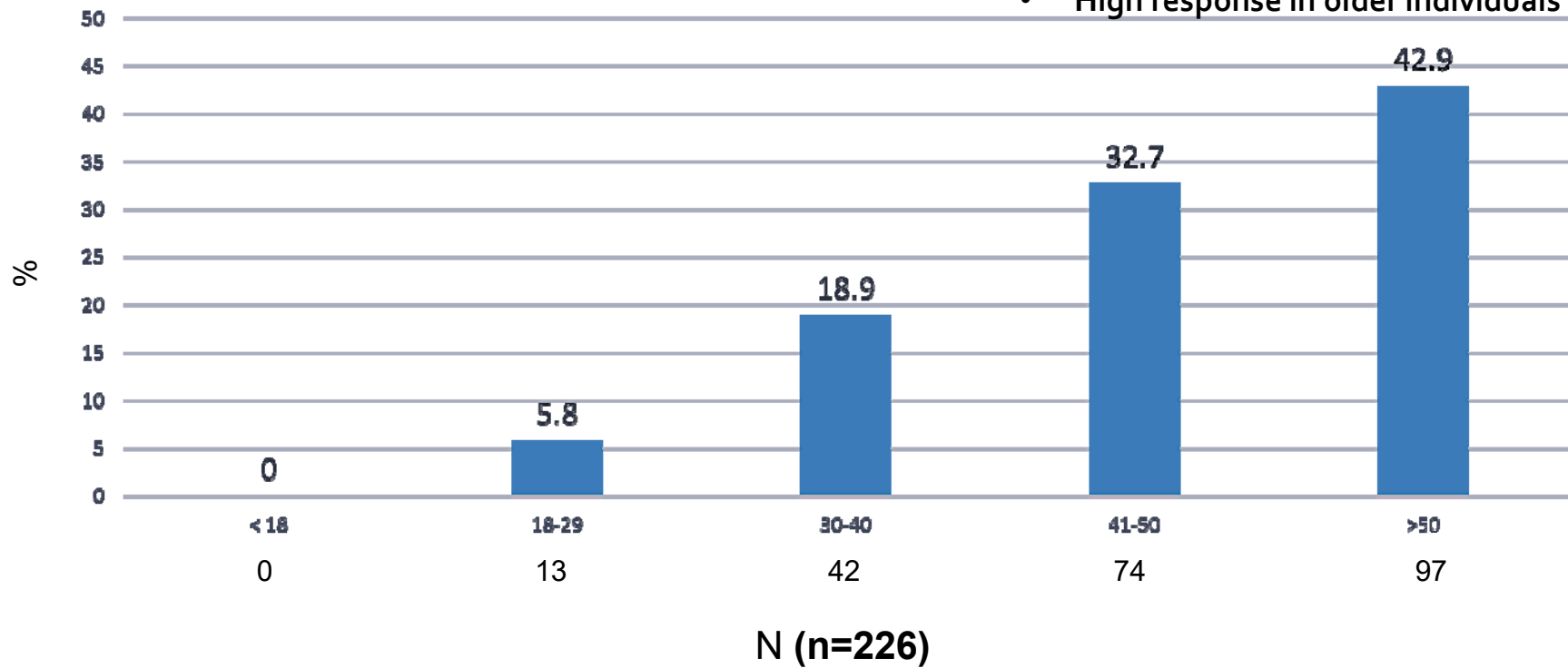
- Somewhat higher response in women
- Female:Male ratio 4.6:1

N=224; 2 no response

# Q2: My age is...

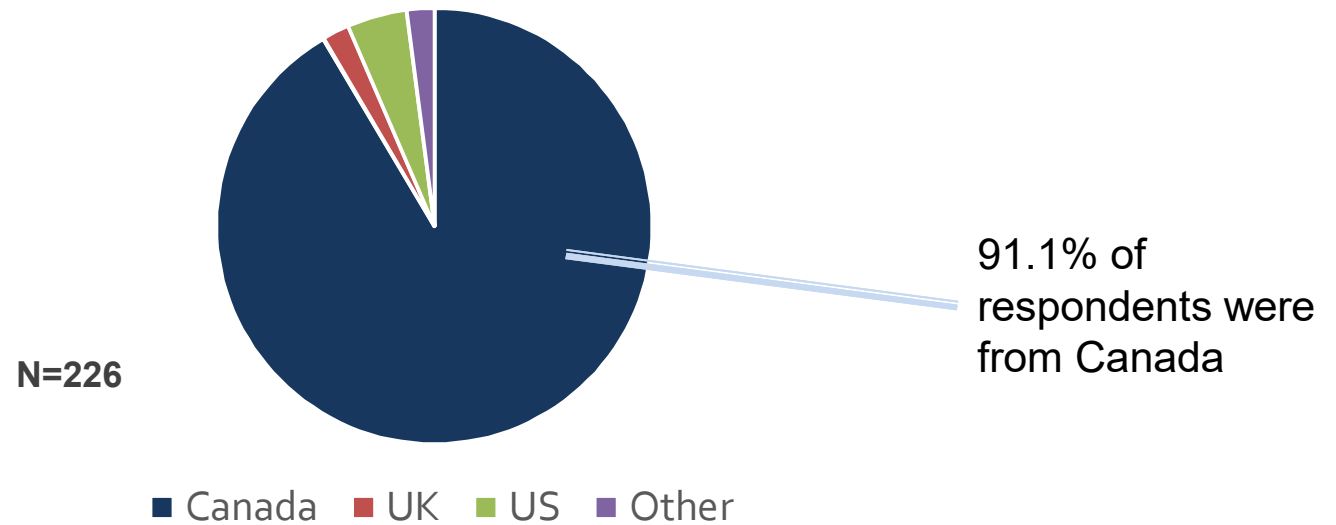
## DEMOGRAPHICS

- High response in older individuals



# Q3: I live in ...

## DEMOGRAPHICS



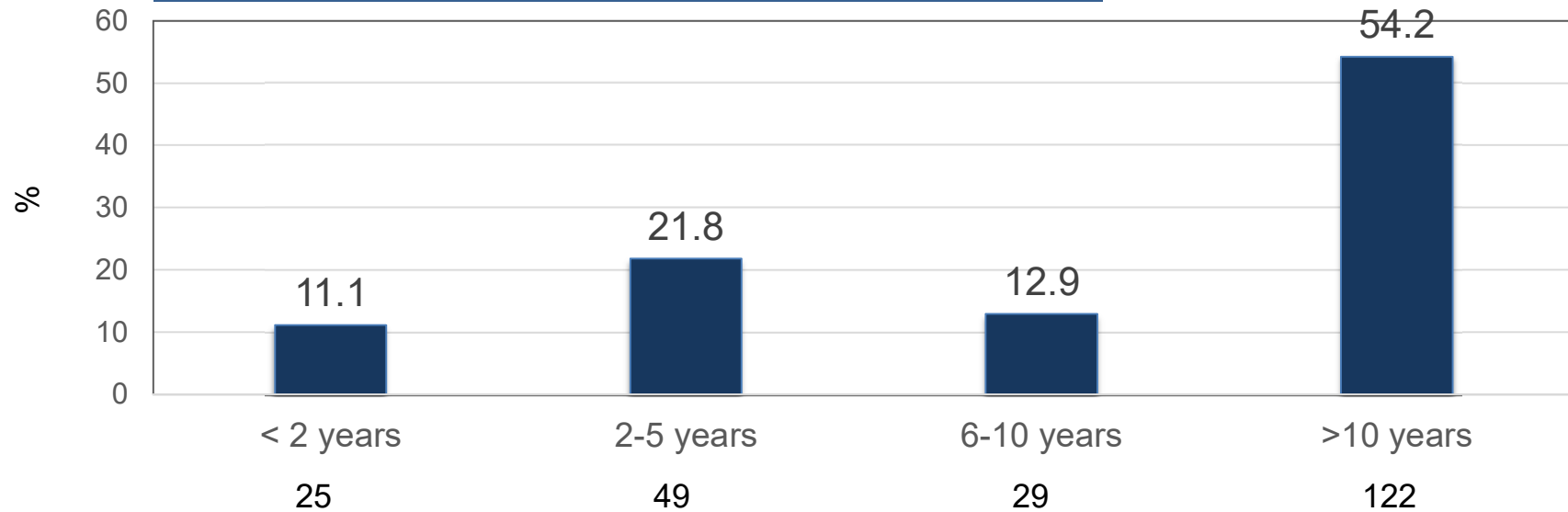
Note: Canadian respondents were not queried about their province

N=248

Analyses on all other slides limited to Canadian cohort

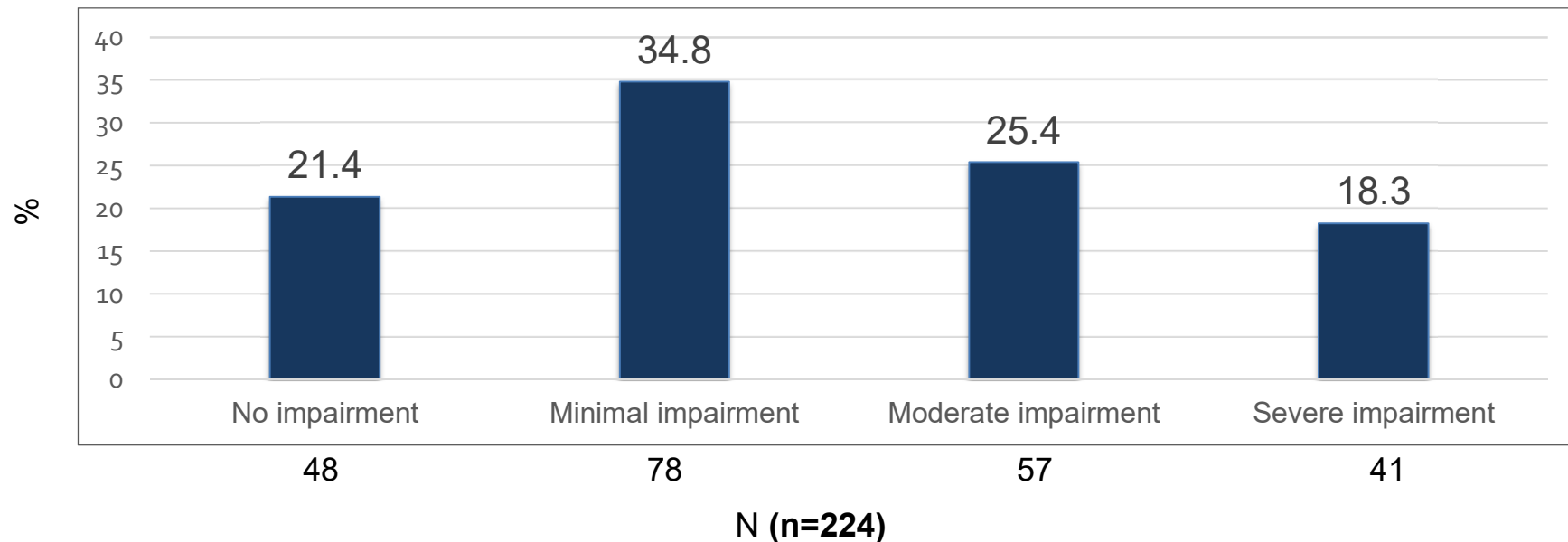
# Q4: I have been living with MS for...

Majority of respondents had long-standing disease, consistent with the older age of the sample



N (n=225)

# Q5: My level of walking ability is...



Defined in survey as:

**Minimal impairment** – can walk unaided

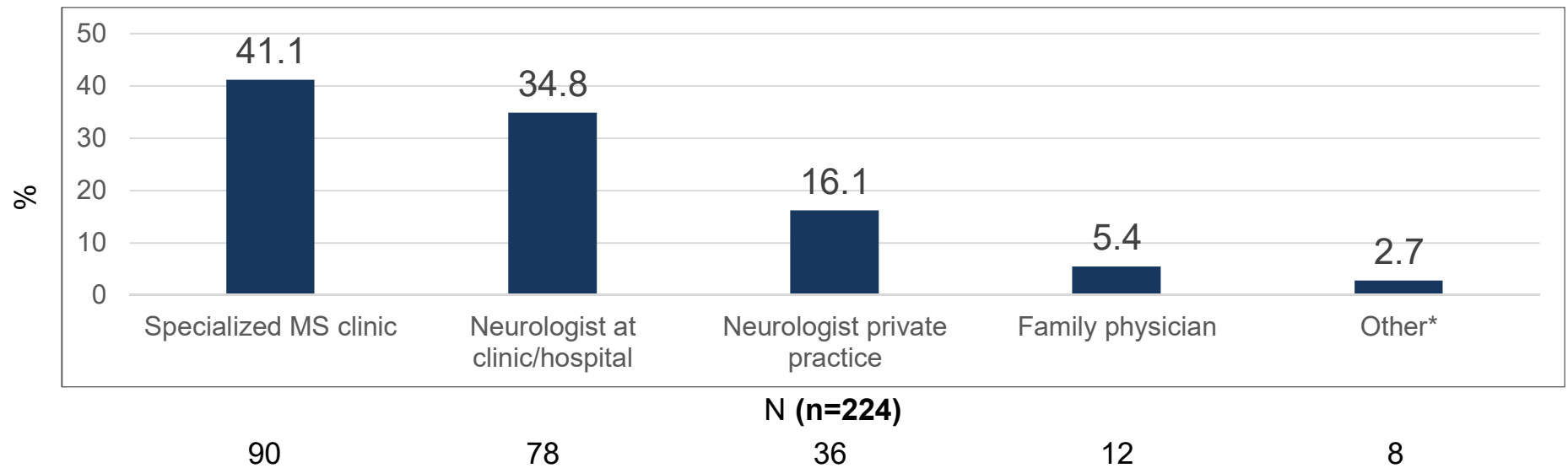
**Moderate impairment** – occasionally/frequently use cane or other assistive device

**Severe impairment** – require a cane, walker or wheelchair



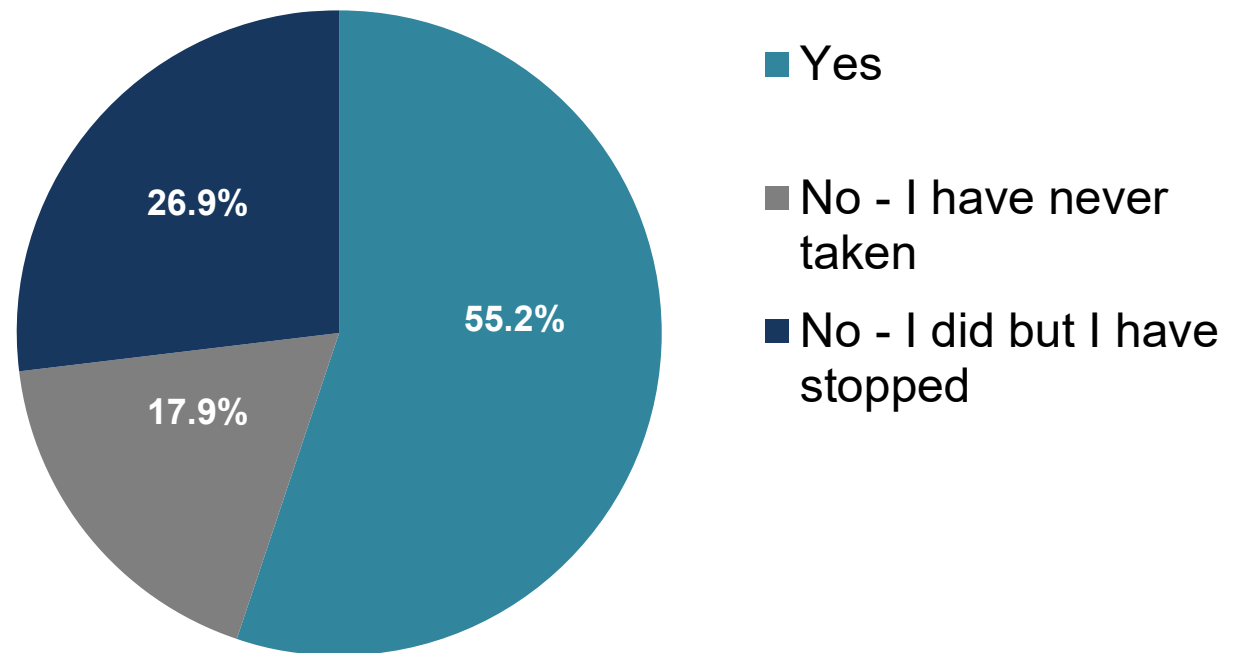
# Q6: My MS is treated at a...

## DEMOGRAPHICS



Other (n=8): No treatment (n=1); naturopath (n=2); GP with annual visits to neurologist (n=2); treated in US (n=1)

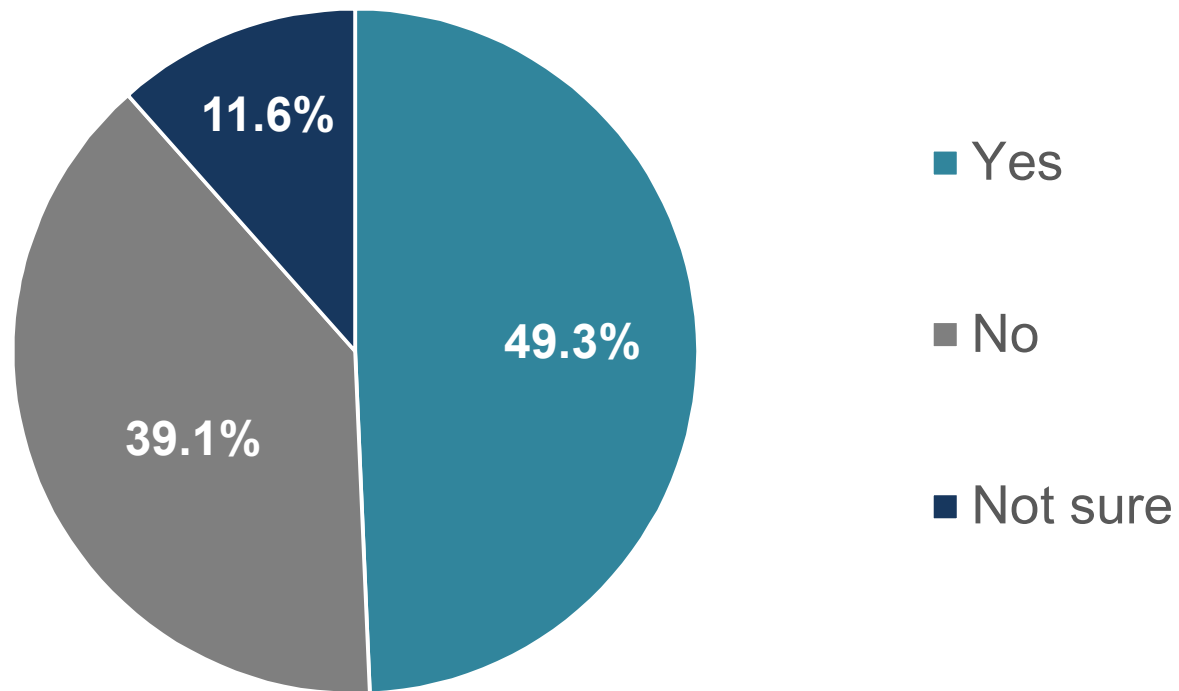
# Q7: I am currently taking an MS medication:



N=223

# Q8: I receive care from a nurse specialized in MS

DEMOGRAPHICS

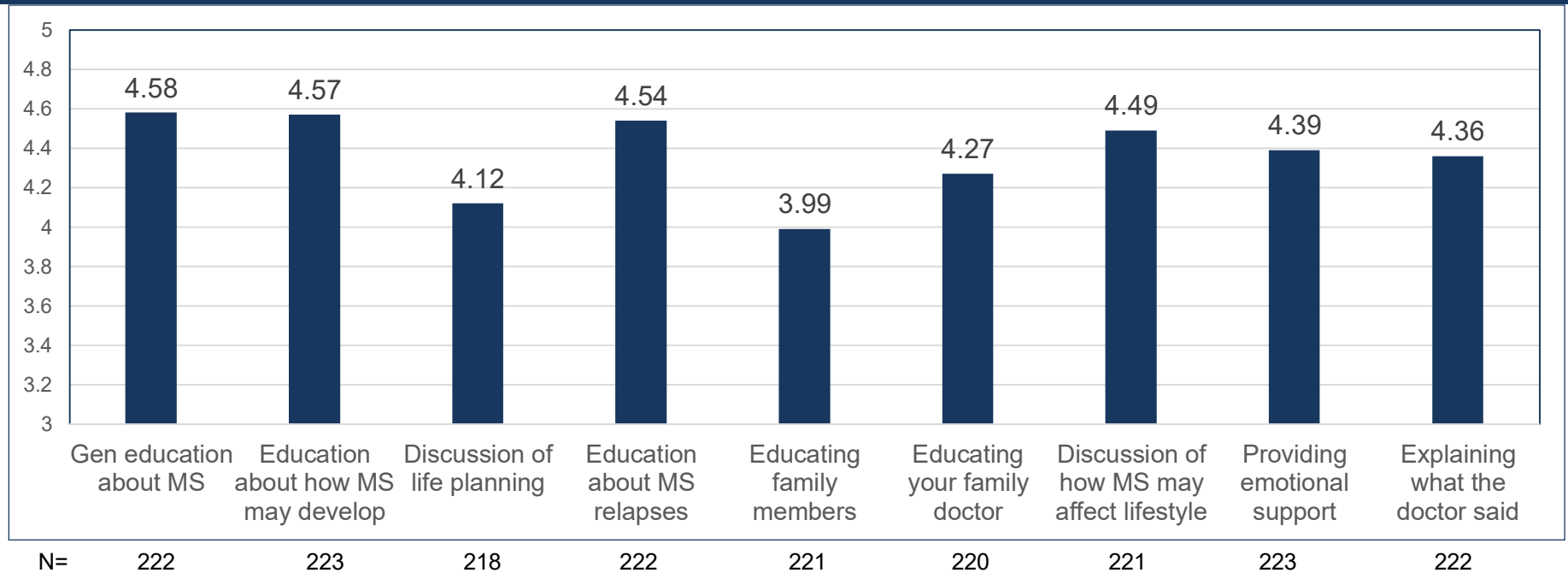


N=225

# Patients' Expectations

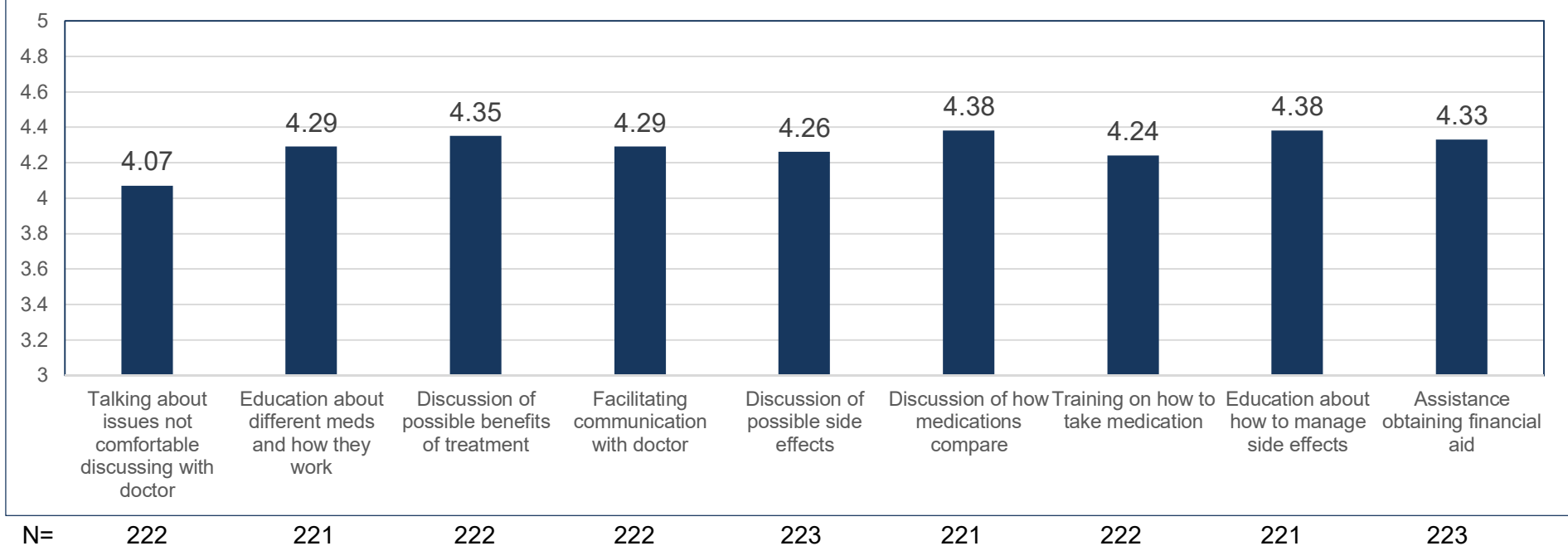
- Provided with a list of roles/tasks
- Asked to rate their importance on 5-point Likert scale:
  - Very important (5 points)
  - Important (4 points)
  - Neither Important/Unimportant (3 points)
  - Not very important (2 points)
  - Unimportant (1 point)
- Scores were averaged according to number of responses

## Q9: When you visit an MS nurse, what services do you expect to receive? (1 of 4)



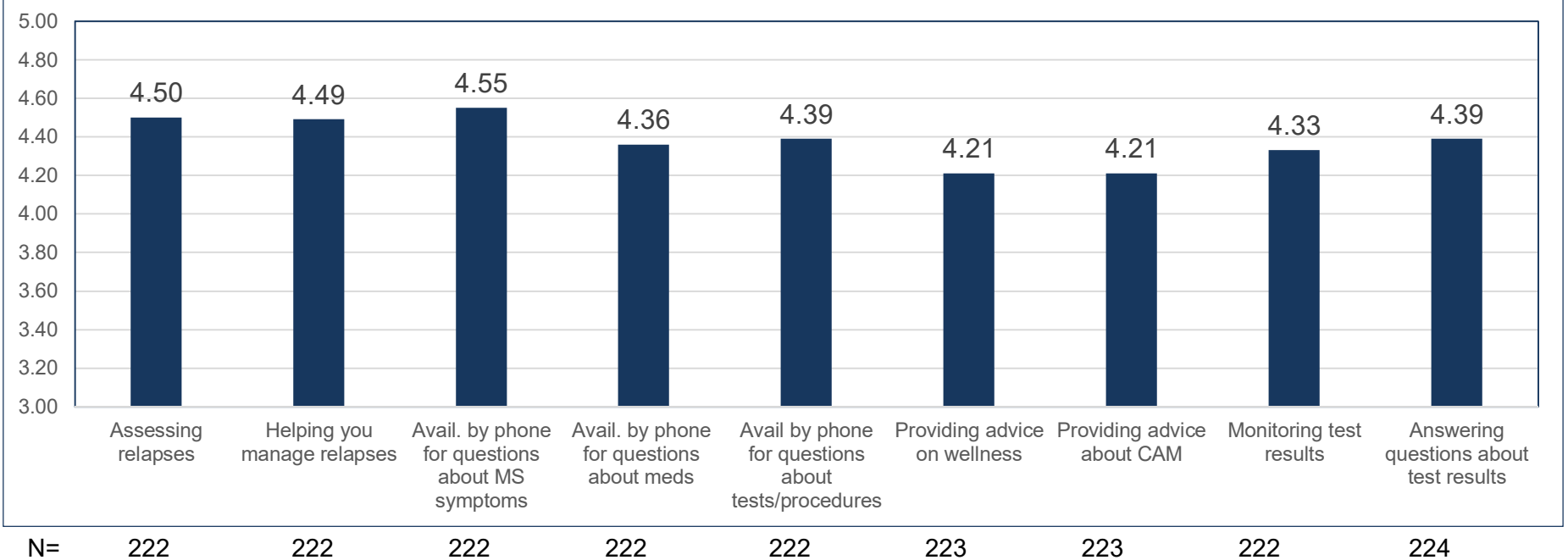
Very important = 5; Important = 4; Neither important/unimportant = 3; Not very important = 2; Unimportant = 1; scores added and averaged for each service

## Q9: When you visit an MS nurse, what services do you expect to receive? (2 of 4)



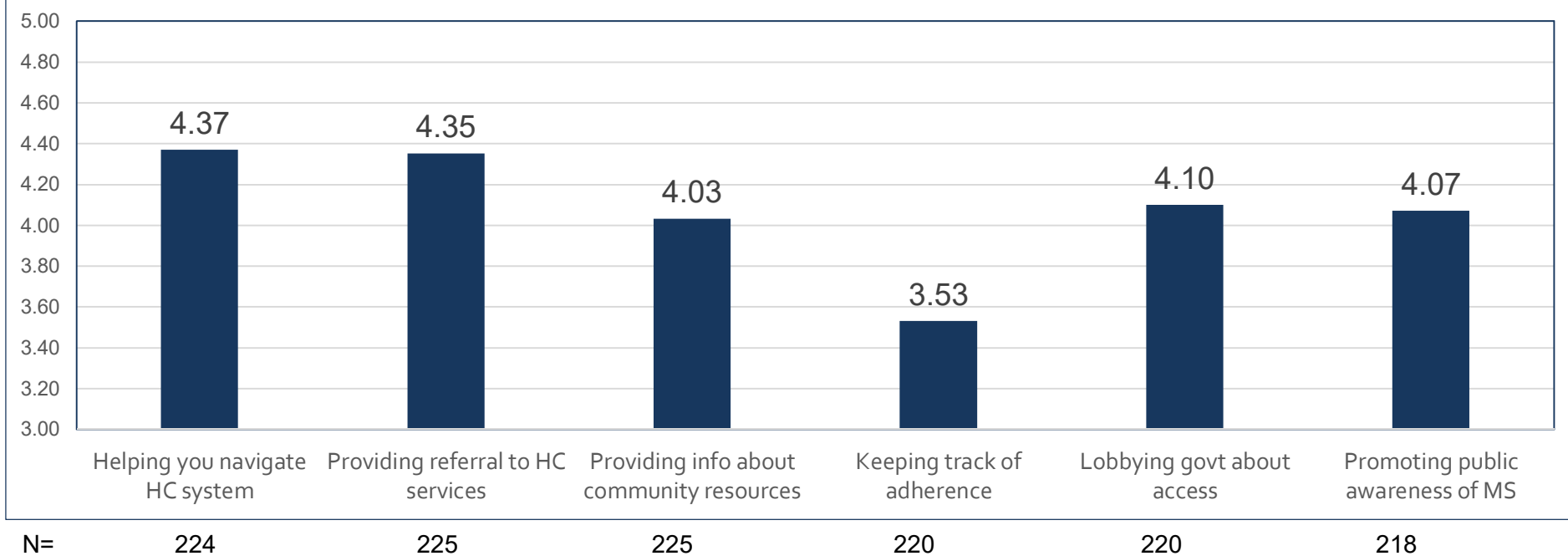
Very important = 5; Important = 4; Neither important/unimportant = 3; Not very important = 2; Unimportant = 1; scores added and averaged for each service

# Q9: When you visit an MS nurse, what services do you expect to receive? (3 of 4)



Very important = 5; Important = 4; Neither important/unimportant = 3; Not very important = 2; Unimportant = 1; scores added and averaged for each service

## Q9: When you visit an MS nurse, what services do you expect to receive? (4 of 4)



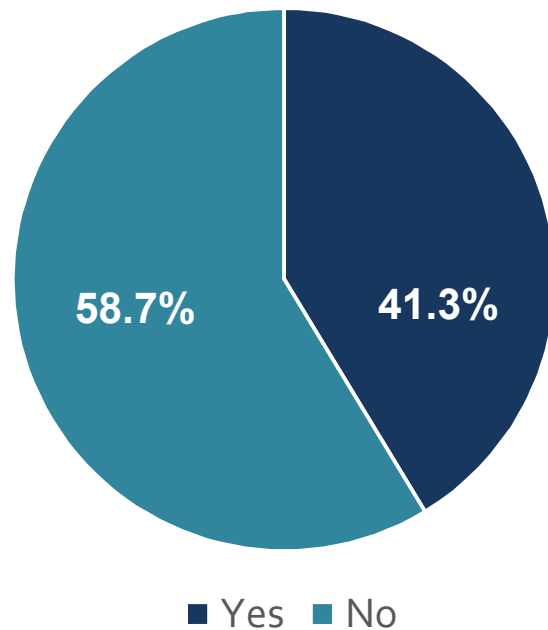
Very important = 5; Important = 4; Neither important/unimportant = 3; Not very important = 2; Unimportant = 1; scores added and averaged for each service



# Most/Least Favored Roles from previous slides

<b>TOP 5</b>		<b>BOTTOM 5</b>	
1. General education about MS	4.58	1. Keeping track of adherence	3.53
2. Education about how MS may develop	4.57	2. Educating family members about MS	3.99
3. Available by phone to answer questions about MS symptoms	4.55	3. Providing information about community resources	4.03
4. Education about MS relapses	4.54	4. Talking about issues they're not comfortable discussing with the doctor	4.07
5. Assessing relapses	4.50	5. Promoting public awareness of MS	4.07

**Q10: Are you in contact with a nurse working for a support program about a specific medication?**



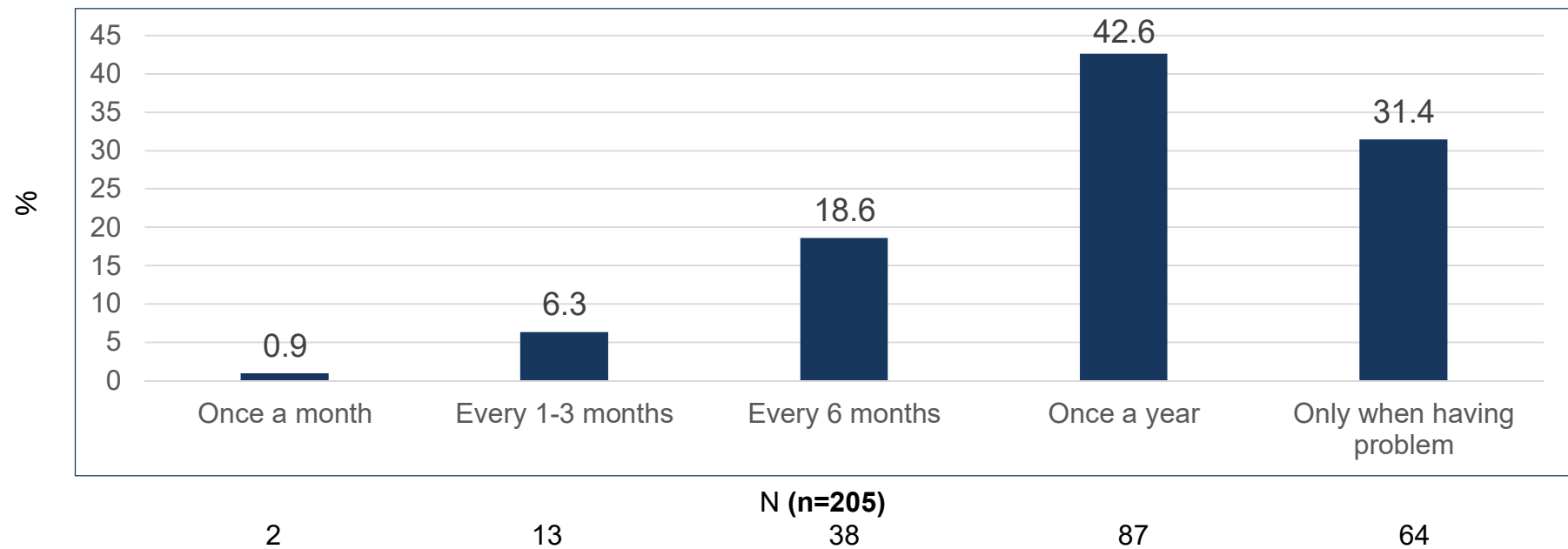
N=225

## Q11: What differences, if any, do you see with respect to the services provided by your MS nurse compared to a nurse at a medication support program?

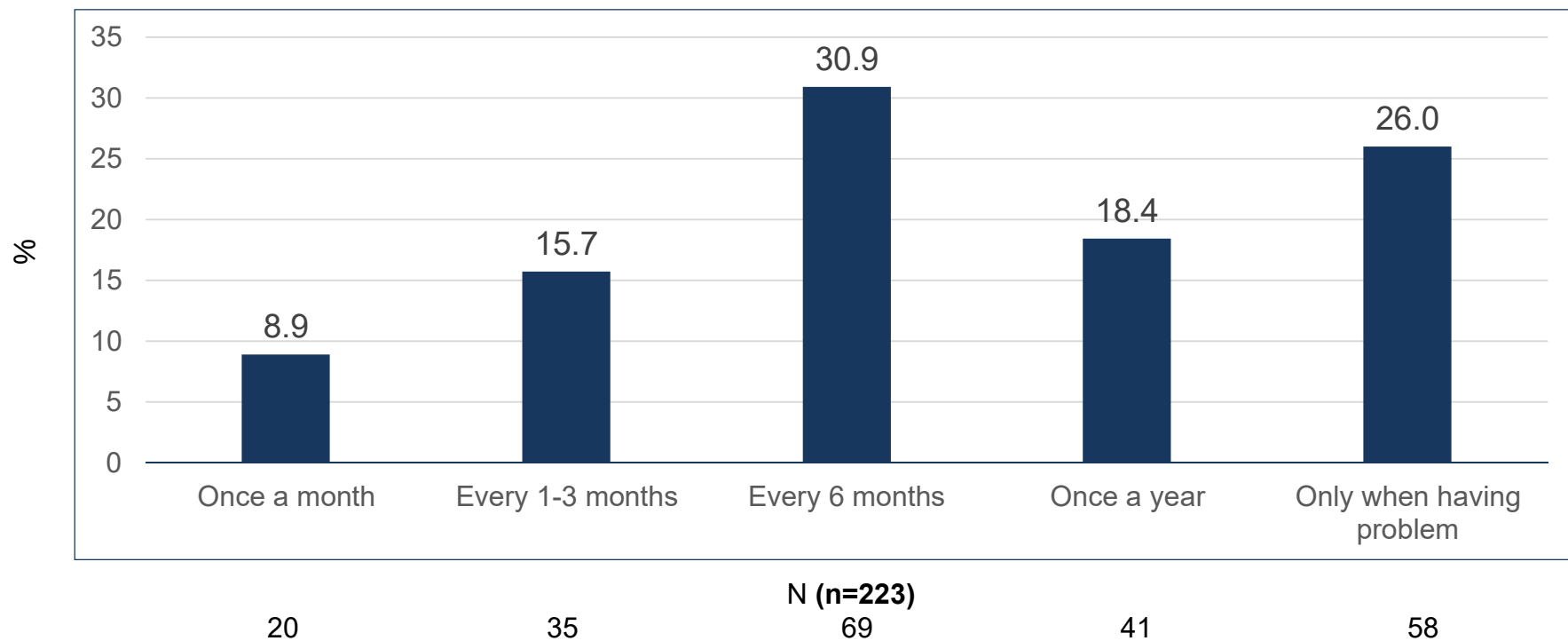
### **General impressions**

- Most common comment: Don't have access to either/no clinic nurse/no PSP nurse/infrequent contact
- PSP nurse easier to contact
  - Typically only discusses the medication
  - No personal contact
- MS nurse less accessible, but meets face-to-face, offers clinical follow-ups (e.g. symptom assessment) and provides more comprehensive information about MS
- One comment that drug companies shouldn't have direct patient contact

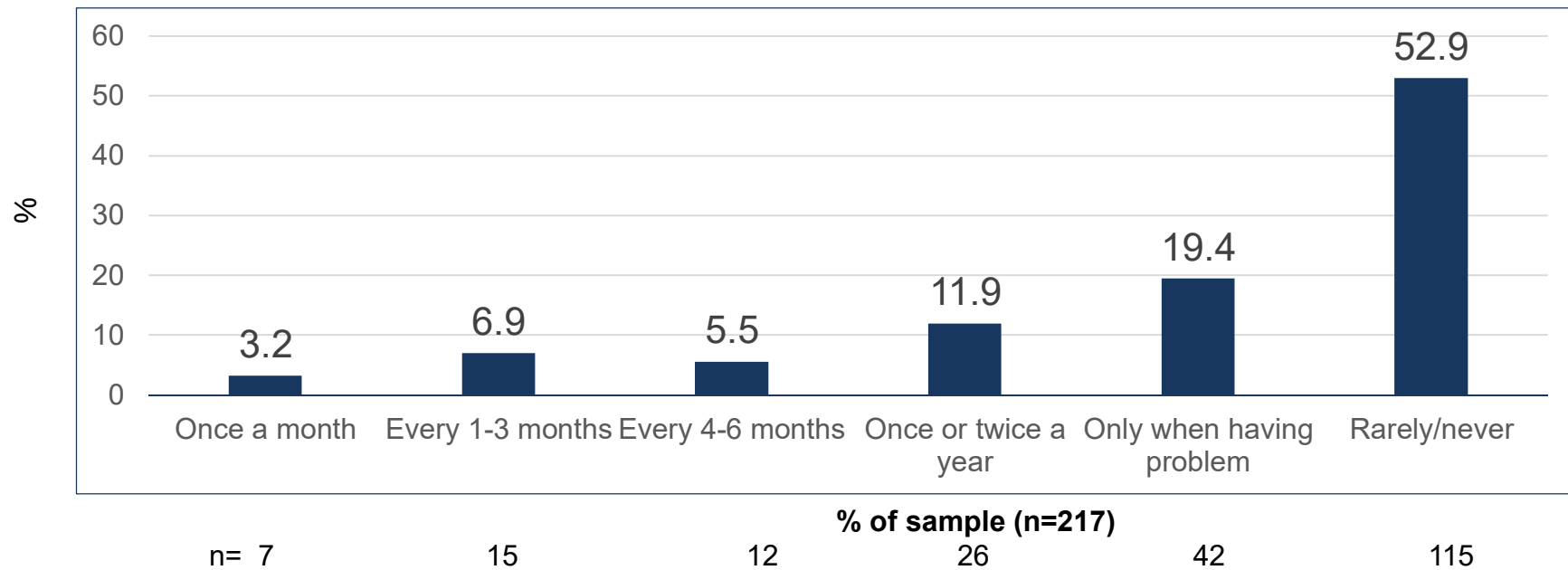
## Q12: How often do you see your MS clinic nurse?



# Q13: How often would you like to see your MS clinic nurse?



## Q14: How often does your MS clinic nurse contact you by phone or email?



**Q15. What problems, if any, have you had that were not adequately addressed by your MS nurse?**

**Key comments**

- Difficulty accessing nurse/phone calls not returned
- Problem symptoms not adequately addressed
- Delays in completing paperwork (e.g. insurance forms)

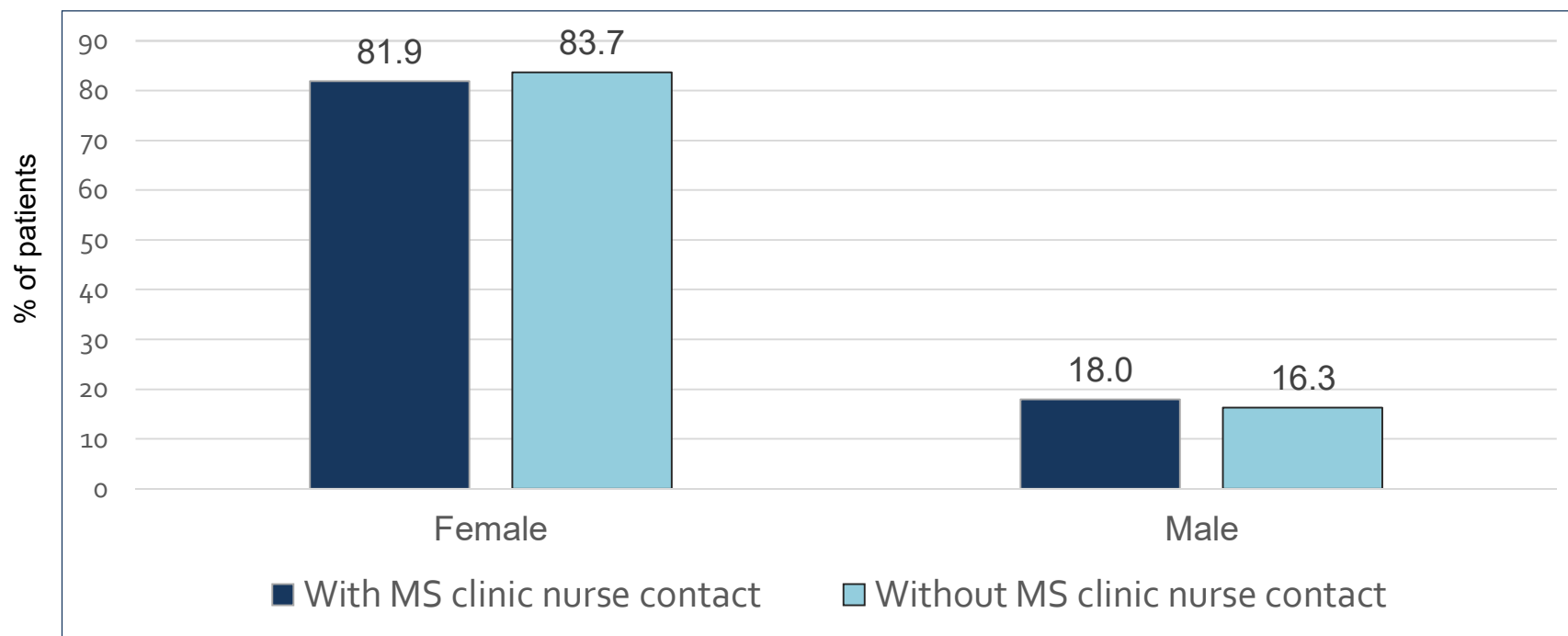
## Q16. Additional comments?

- Generally positive comments about MS nurses
- Difficulty accessing MS clinic
- Difficulty accessing MS nurses
- Would like email access
- Nurses are overworked/too busy/have inadequate resources
- Would like referral to non-drug services/resources
- Would like nurses to use a symptom checklist so patient doesn't have to initiate conversation



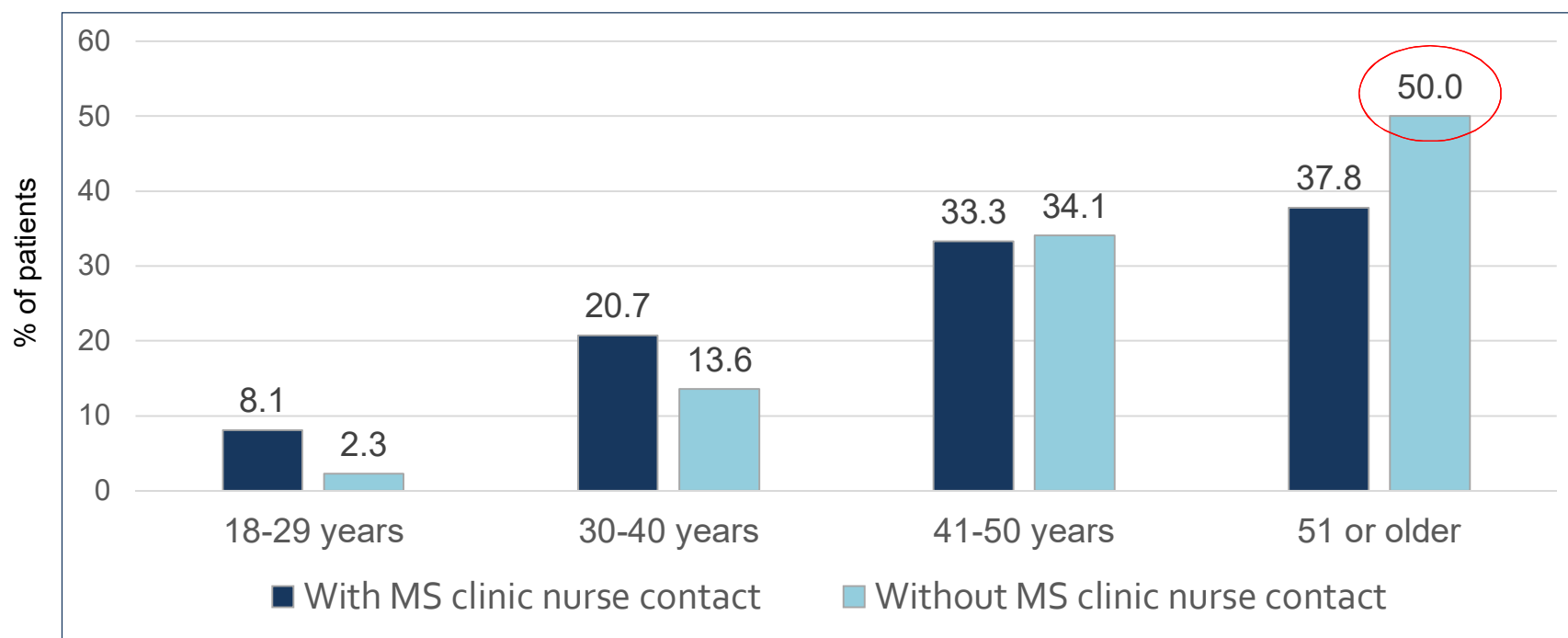
## People with vs. without contact with an MS clinic nurse

# Sex



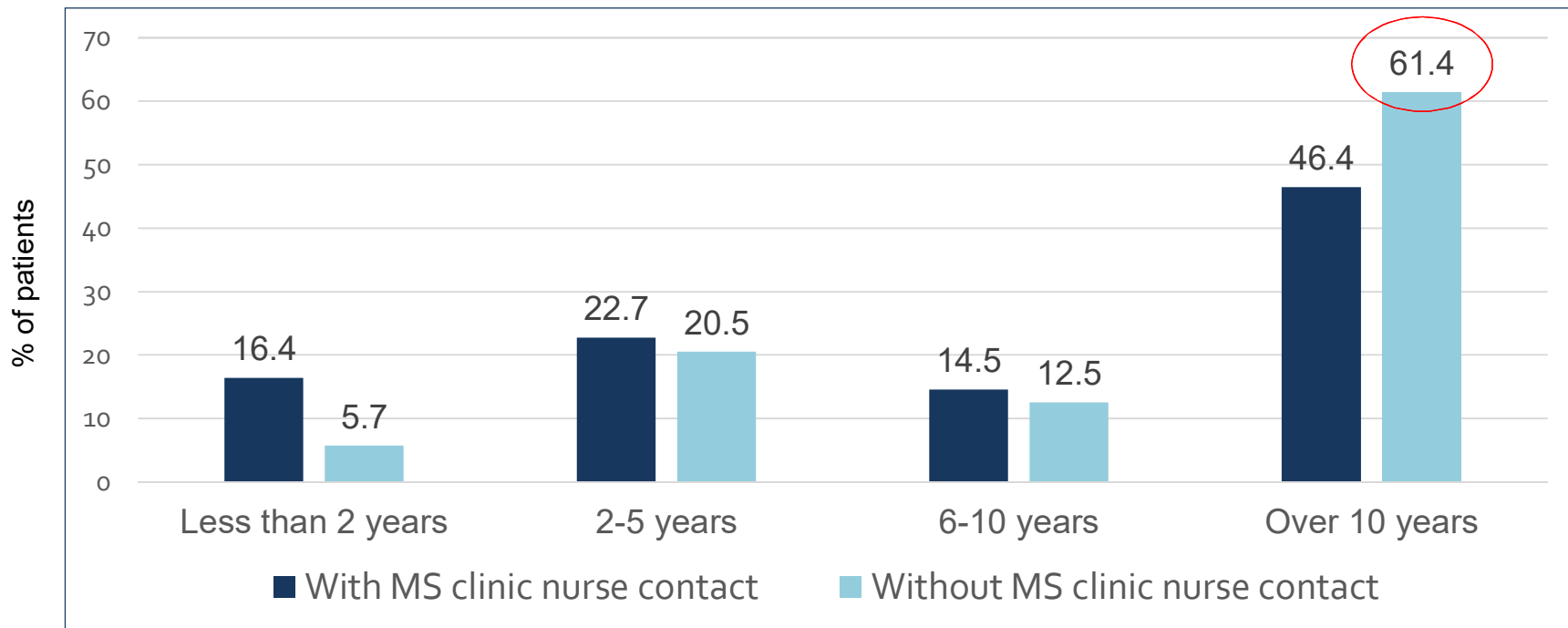
# People with vs. without contact with an MS clinic nurse

## Age



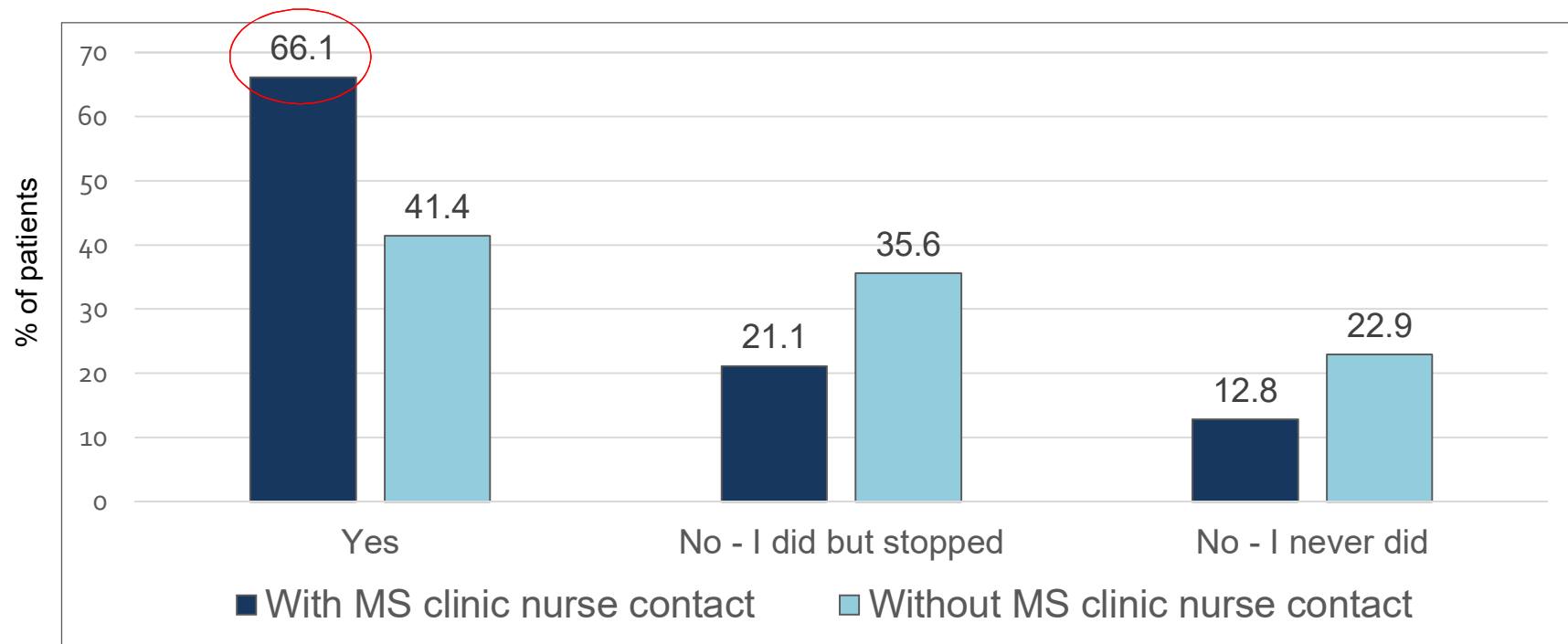
# People with vs. without contact with an MS clinic nurse

## Duration of MS



# People with vs. without contact with an MS clinic nurse

## Medication status



# Conclusions

- Patients highly rate the value of MS nurses in:
  - Educating them about their diagnosis and prognosis
  - Assessing and managing relapses
- Respondents were generally older and most did not have access to MS specialist nursing care
  - May contribute to the high proportion (45%) of patients who were untreated or had stopped taking a DMT
- Results support the central role of nursing in the day-to-day management of MS patients

# Future Inquiry

- Develop and evaluate disease specific education strategies and materials
- Further exploration of MS specific needs of older patients with out regular access to MS nurses or clinics
- Evaluate strategies for improving access to nurses in clinics – e.g. email