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Smoking habits, awareness, and support needs for cessation: A survey of people with multiple sclerosis

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Abstract

Objectives: To assess smoking habits, nicotine use, exposure to passive smoking, awareness of associated harms, and experiences with and preferences for smoking cessation support amongst people with multiple sclerosis (MS).

Design: Online survey.

Setting: Community.

Participants: Adults living in Australia with probable or diagnosed MS were recruited via social media, and newsletters to participate in an online survey in 2020.

Results: Of the 284 participants, 25.7% were current smokers, 38.0% were former smokers, and 36.3% were never smokers. Awareness of smoking harms on MS onset and progression was low. Almost a quarter (23.8%) of participants were regularly exposed to passive smoke. Among current smokers, 76.1% had tried quitting (28.2% in the previous year) and 73.2% considered quitting within 6-months. Many participants reported perceived short-term benefits of smoking, and long-term benefits of quitting, on MS symptoms and general wellbeing. While most participants reported that healthcare providers, including neurologists, had assessed smoking status, very few had provided help with quitting. Most current smokers preferred speaking about smoking to a neurologist or general practitioner and almost 60% felt they needed additional cessation information specific to MS. If they received information about the MS-related benefits of quitting, 45.5% would be motivated to quit smoking, with 40% wanting information/advice at the point of MS diagnosis.

Conclusions: There is an urgent need for evidence-based smoking cessation supports for people with MS. MS clinicians, in collaboration with patient organisations, smoking cessation services, and general practitioners should make smoking cessation promotion with people with MS a priority.

Article Summary:

Strengths and limitations of this study:

- This is the first survey to assess variables related to tobacco smoking perspectives and behaviour in people with MS.
- The study expands on perspectives of people with MS with relation to what and when smoking cessation information is provided, enabling targeted time-critical support.
- There is potential for bias related to self-selection in the study, which could lead to an overestimation of the prevalence of smoking, but underestimate the lack of knowledge about the relationship between MS and smoking.
- Reporting past quit attempts and healthcare professionals' advice may be subject to recall bias.
- Caution should be taken in generalising to other countries beyond Australia, as knowledge gaps and related concerns may be worse in countries where there is less focus on tobacco control.

Introduction

Current evidence indicates that genetic and environmental factors contribute to multiple sclerosis (MS) risk[1] and tobacco smoking has been identified as a key modifiable risk factor.[2] Smoking tobacco presents considerable health risks to people diagnosed with MS,[3] with evidence for a causal association between smoking and MS progression.[4-6] Furthermore, studies in people with MS report associations between tobacco smoking and worse fatigue, depressive symptoms and health-related quality of life[7]; higher relapse rate during interferon beta treatment[8] and natalizumab treatment[9]; more co-morbidities such as heart disease[10]; and higher premature mortality.[11]

Evidence is emerging that people with MS are largely unaware of the risks of smoking to MS, and that there are MS-specific barriers to quitting, such as the potential impact of cessation-induced stress on MS.[12-14] Our qualitative work also identified several MS-specific barriers to smoking cessation, including concerns that quitting may negatively impact MS symptoms, such as mood, cognition, pain, and relapses.[14] Some participants were also unsure whether nicotine replacement therapy (NRT) or other cessation medications would be safe to use for people with MS, or in combination with common MS medication, an indication that needs of people with MS in relation to smoking cessation were not met.[14]

The current study aimed to assess whether people with MS (regardless of smoking status) were aware of the links between smoking, including passive smoking, and MS. Furthermore, we aimed to quantitatively assess smoking habits, motivators for smoking, barriers and facilitators to smoking cessation, and cessation preferences of people with MS who were current or former smokers. If there are MS-specific barriers to cessation, a lack of tailored support and information that goes beyond tools designed for the general population is likely to mean less successful cessation.[3]

Methods

Research ethics approvals and consent

This study was approved by the ethics committee at The University of Melbourne (HREC-1954916.3), and conforms to the STROBE guidelines for cross-sectional studies.[15] Participants provided digital consent before entering the survey.

Participants and recruitment

People living in Australia aged 18 years and older with probable (neurologist-diagnosed clinically isolated syndrome or first demyelinating event) or diagnosed MS were invited to participate via

websites, newsletters and social media channels of relevant organisations in Australia (MS Australia, MS Research Australia, and the MS state societies) and MS support groups. Data were collected over 11 weeks between May and July 2020.

Survey

The survey consisted of approximately 75 questions, with a mix of multiple-choice, matrix table and text entry questions, using display logic to direct participants to relevant questions consistent with previous responses using the platform Qualtrics.

The survey collected demographic and clinical information including level of disability using the Patient Disability Disease Steps.[16] Remoteness of residential location was derived from postcodes.[17] Participants were asked about smoking habits, knowledge of and experience with smoking, passive smoking, smoking cessation, nicotine products, interactions with healthcare providers regarding smoking-related topics and preferences for smoking cessation support.

Data analysis

Stata/SE 16.1 was used for all analyses.[18] Descriptive statistics are presented for survey responses, stratified by smoking status when relevant. Median and interquartile range (IQR) were calculated for continuous variables that were not normally distributed. In some instances where several multiple-choice options were offered, categories were combined for presentation in the results. Integrity of the data was checked to identify and remove ineligible participants, bots (automatically flagged by Qualtrics), duplicate responses or mostly incomplete responses (less than 20% of survey items). We conducted a complete case analysis, and percentages were calculated based on the number of participants that completed that item, reported in each section.

Patient and Public Involvement (PPI)

The survey instrument was constructed from the results of previous in-depth qualitative interviews assessing the perspectives of 25 people with MS who were current or recent smokers[19] and research team expertise, which included a person with MS, a former smoker, smoking cessation experts, MS researchers, clinicians, and cessation advocates. Four volunteers not involved in the study pilot-tested the survey.

Results

After removing 29 records (n=1 bot; n=1 duplicate; n=2 did not consent to participate; n=3 did not have either definite or probable MS; n=22 exited survey before completing 20% of survey questions), the final convenience sample comprised 284 participants, 90.1% of whom completed all survey questions relevant to them.

Demographic and clinical information

Most (88.0%) participants were women, and the median age was 46 (IQR 38-56.5). Almost all participants (278, 97.9%) reported a neurologist-confirmed diagnosis of definite MS and median years since diagnosis was 7 years (IQR 2-16, range 0-39 years). Other characteristics are reported in Table 1.

Awareness of the relationship between smoking and MS

Most participants were unaware of the associations between smoking and MS onset, progression or treatment (Table 2). Those 150 participants who were aware of at least one of the risks were asked how they obtained this information. The most common sources for this information were MS healthcare providers (42.7%), online information (36.0%), MS societies (26.7%), guessing (18.0%), general practitioner (9.3%), family member or friend (4.0%), and other (12.7%).

Smoking habits and nicotine use

As reported in Table 3, 73 participants (25.7%) were current smokers (67 daily, 6 weekly) and 38.0% were former smokers. Use of nicotine vaping products (n=14) and NRT (n=12) was reported by 23.6% of current smokers (n=17) and 8.3% of former smokers (n=9), but none of the never smokers. Almost half of the current smokers (43.7%) and 17.1% of non-smokers reported being exposed to passive smoke regularly, while 10.0% of non-smokers and 39.4% of smokers lived with someone who smoked.

Of those (n= 43) current and former smokers who made a quit attempt in the past two years, less than half (n=20, 46.5%) used NRT, while some used other stop-smoking medication (n=12, 27.9%), advice from healthcare provider (n=12, 27.9%), internet sites for quitting advice and support (n=10, 23.3%), or mobile phone-based programs (n=9, 20.9%). Only 18.6% indicated they quit without any cessation support. Most current smokers reported attempts to quit in the past (76.1%), and 28.2% reported attempts to quit in the past 12 months. Quit attempts commonly lasted less than 1 month in duration (44.4%). Approximately half of the former smokers (51.4%) had quit smoking before MS diagnosis.

Motivators to continue smoking

Almost all current smokers (n=72, 1 missing) reported to smoke to cope with stress (70.8%), to have time out/a break (61.1%), for enjoyment (48.6%), as a distraction (34.7%), for something to do when their mood is low (34.7%), and to prevent nicotine withdrawal symptoms (30.6%). Some reported smoking for something to do when isolated (22.2%), because their partner or other person in their household smokes (13.9%), to cope with MS symptoms (12.5%), or for something to do when unable to work (8.3%).

Readiness and motivators to quit

Of 71 current smokers, 21.1% considered quitting in the next 30 days, and an additional 52.1% in the next 6 months. Their motivators to quit included to improve general health (96.2%), MS or MS symptoms (57.7%), for financial reasons (51.9%), and for family, partner, and friends (32.7%), and social pressure (13.5%). Some current smokers were not seriously thinking of quitting in the next 6 months (14.1%) and some were not at all interested in quitting (12.7%).

Short-term health-related changes after smoking

Current smokers were asked whether they noticed short-term changes in symptoms or wellbeing immediately after smoking. The majority reported that most symptoms, in particular stress and anxiety, improved immediately after smoking, except fatigue where more reported worsening although numbers were low (Table 4).

Long-term health-related changes after smoking cessation

Participants who had ever quit smoking for more than 4 weeks (regardless of current smoking status), were asked about health-related changes after quitting for symptoms that were relevant to them. A large majority of those who remembered, reported that sense of wellbeing improved after quitting for longer than four weeks, and many reported improvements in symptoms such as stress, anxiety, and fatigue. Few reported worsening of symptoms after quitting for longer than four weeks (Table 5).

Smoking cessation concerns

Of the 71 current smokers who reported concerns regarding smoking cessation, most cited negative effects on mood (60.6%), and the process being too stressful (53.5%) and difficult (scared they could not quit) (49.3%), an increase in boredom (28.2%), side effects of quitting medications (21.1%), an

MS relapse due to the stress of quitting (19.7%), worsening of symptoms (14.1%), and smoking cessation medications interfering with MS medication (14.1%).

Healthcare providers and cessation support

Among current smokers with a current neurologist (n=67), only 1 participant reported that their neurologist had provided assessment, advice as well as support with quitting (Table 6). A lower proportion of current smokers reported that their public neurologist assessed their smoking status (80.8%) and advised to quit (38.5%), compared to those visiting private neurologists (asked about smoking status: 95.1%, advised to quit: 61.0%). Of current smokers with a neurologist, 77.6% reported that their neurologist was aware of their smoking status. Most participants (70.0%) reported that healthcare providers other than MS clinicians had asked them about smoking (Table 6). Of current smokers who were seeing health professionals other than MS clinicians, 85.3% reported that their general practitioner was aware of their smoking status.

Of current and former smokers, 28.7% reported that they were satisfied with the cessation support that they received from their healthcare providers, while 61.7% were neither dissatisfied nor satisfied, and 9.6% were dissatisfied (similar for current vs former smokers). More than one third of current smokers reported that they would feel disappointed if none of their healthcare providers discussed smoking with them (38.2%), some would feel relieved (13.2%), and the rest (47.1%) selected a neutral response.

Preferences for smoking cessation support

Most current smokers (n=69, 4 missing) reported a preference to speak about smoking with their general practitioner (59.4%) or neurologist (52.2%), with fewer mentioning an MS nurse (34.8%) and a pharmacist (17.4%). Only 5.8% preferred not to speak with any healthcare provider. Half of the current smokers ranked the importance of receiving cessation support from people with knowledge about MS as extremely or very important (50.7%).

Of the current smokers, more than half (59.4%) reported that they need additional cessation information specific to MS (regardless of readiness to quit). If current smokers were to receive information about the MS-related benefits of quitting, 45.5% reported they would be motivated to quit smoking and an additional 19.7% would be motivated to reduce smoking. However, 19.7% reported that such information would not affect their smoking habits, and a small proportion expected that such information would elicit guilt and stress, causing them to smoke more (12.1%).

Current smokers were asked when they thought people with MS should be offered information about the benefits of quitting. Preferred times were at the time of diagnosis (40.9%), within 1 month of diagnosis (24.2%) and at a later time (22.7%), while 4.5% said never.

Importance of receiving cessation support from people with knowledge about MS

Just over half of 69 current smokers expressed interest in a special program for smokers who have MS (56.5%) and NRT (50.7%). Other cessation support of interest included stop-smoking medications (34.8%), advice from their neurologist or MS nurse (31.9%), face-to-face advice from a smoking cessation expert including counselling (30.4%), advice from another doctor or healthcare provider (24.6%), mobile-based programs such as phone apps (23.2%), and a workbook with tips and exercises (23.2%). Less than 15% showed interest in either hospital-based service, web-based program, internet sites for quitting advice and support, information brochures and booklets, online support group or telephone Quitline service. Only 8.7% stated that they did not want support for quitting. Topics that at least 75% of current and former smokers who quit after MS diagnosis thought were important for quit services to address included (in order of importance): Interactions of anti-smoking medication with MS medication, benefits of quitting on MS, side effects of anti-smoking medication, effect of stress due to quitting on MS relapses, temporary worsening of symptoms due to quitting, benefits of quitting on general health, challenges people with MS might face, effect on mood, withdrawal symptoms of quitting smoking, weight gain, and effect on relationships.

Discussion

Smoking prevalence is higher in our sample of Australian adults with MS (25.7% were current smokers, of which 23.6% daily smokers, and 38.0% former smokers in our sample) compared to the 2019 national average estimates for adults at 11.6% daily smokers and 24.3% former smokers.[19] Current smokers in our study were commonly long-time heavy smokers who had attempted to quit in the past. More than a quarter of current smokers (28.2%) had attempted to quit in the previous year (similar to 31% in the general population[19]) and the majority considered quitting in the next 6 months. Almost a quarter of all participants, including 17.1% of non-smokers, were regularly exposed to passive smoking, which may also increase the risk for poor health outcomes.

One of the top motivators for quitting was to improve MS and related symptoms, which indicated a general belief that smoking is harmful for MS. However, our results showed extremely low levels of awareness of adverse effects of smoking and passive smoking on MS onset, progression and

treatment in our sample. This lack of knowledge of a modifiable risk factor represents a failing in caring for people with MS, and is consistent with other studies.[12-14] There is an urgent need for remedial education and action to ensure better promotion of smoking cessation as an integral part of MS care. Since information about relevant health consequences contributes to the success of cessation interventions for other groups, better education should contribute to smoking cessation success as well as avoidance of passive smoke exposure in people with MS.[20]

Unsurprisingly, people with MS experience many of the same motivators to continue smoking as people in the general population, including stress-relief,[21] which is not surprising since nicotine causes an immediate sense of relaxation.[22] The reported motivators to cope with stress and low mood may be more of an issue for people with MS since they experience higher levels of anxiety and depression than the general population.[23-25] When promoting smoking cessation, it needs to be acknowledged that many participants reported immediate benefits from smoking such as perceived well-being, which are likely major barriers to cessation attempts and success.

In the long-term however, more participants reported improved rather than worsened stress and anxiety after quitting for longer than 4 weeks. This is consistent with evidence that smoking is not an effective long-term strategy of dealing with stress and anxiety.[22 26] Reported improvements in sense of wellbeing and fatigue after quitting for longer than a month are also consistent with the literature.[27] Bladder and/or bowel problems was the only symptom group for which slightly more participants reported worsening rather than improvement after quitting, albeit most reported no change. Overall, these results strongly indicate that there is a need to support people with MS to find less harmful ways to maintain or enhance moment-to-moment well-being.

Australian guidelines state that smoking cessation should be a key component in chronic disease management.[28] However, less than 30% of current and former smokers in our study were satisfied with the cessation support that they received from their healthcare providers, consistent with our qualitative findings that the information and support needs of people with MS are often not met.[14] Even though most smokers reported that their neurologist had enquired about their smoking status, only half reported that their neurologist advised cessation, and only one participant reported that their neurologist provided support to quit, such as pharmacotherapy or referral to a cessation service. Further, less than one third of current and former smokers who quit in the past two years received support from a healthcare professional. The Australian guidelines for smoking cessation recommend the use of NRT or stop-smoking medications,[30] which generally increase cessation

success by 50-60%[29]; however, less than half of the current and former smokers who quit in the past two years used NRT and less than one third used smoking cessation medications. These findings are consistent with those from the Australian general population, showing that people more commonly attempt to quit 'cold turkey', rather than using NRT or medication, or advice from a healthcare provider.[19]

Our findings indicating inadequate support for smoking cessation, coupled with the poor awareness of smoking risks, indicates that critical opportunities to educate about smoking and promote cessation are missed. This gap in MS healthcare is mirrored in the management of other smoking-related diseases, such as in cancer management by oncologists in Australia.[30]

Implications for practice

Health providers should be supported to follow evidence-based guidelines for promoting smoking cessation, including regularly assess smoking status, providing information and advice about the benefits of quitting on general health and MS, as well as smoking cessation support[30] to people with, or at risk for, MS who smoke and are interested in quitting.[3 31] A major focus of support should be on finding ways to help people with MS to manage their well-being without smoking; this is likely a more salient issue for them than for smokers in the general population.

Depending on the clinicians' capabilities and resources, providing cessation support might include referrals to smoking cessation services, counselling services specialised in behaviour change, prescribing NRT and/or other smoking cessation medications, and arranging extra support with symptom management. Further, smoking cessation services likely need to improve their understanding of concerns related to MS-specific barriers to smoking cessation, including potential management of mood disorders and other MS-related symptoms, which might temporarily worsen. Many participants were interested in a program for people with MS who smoke, and tailored approaches to cessation support have proven helpful in other populations such as pregnant women and cancer patients.[20 32] While general practitioners may be better placed to spend time providing smoking management on a regular basis, MS clinicians may also have an important role in promoting smoking cessation and communicating its importance in relation to MS.[14] Information provision is particularly important around the time of diagnosis, which is a time when people with MS may be most motivated to make behavioural changes,[14] in line with literature on the so-called "teachable moment".[33] However, continuing support will be needed for those unable to make or sustain such a

change in the stressful period following diagnosis, and to prevent smoking relapse among those initially successful.

Research is needed to understand whether collaborative efforts from the MS community (MS clinicians, patient advocates, allied health professionals) with GPs and smoking cessation experts increases cessation success in people with MS over time.

Strengths and limitations of the study

To our knowledge, this is the first survey to assess variables related to tobacco smoking in MS. The main limitation is the potential for bias related to self-selection into the study, with those who smoke, but perhaps not those self-conscious that they smoke, and those more interested in smoking cessation more likely to participate. This could lead to an overestimation of prevalence of smoking. However, if our assumptions are correct, it might, as indicated above, underestimate lack of knowledge about the relationship between MS and smoking. As a result, the prevalence estimates should be treated as indicative rather than precise. We also recognise that reporting past quit attempts and healthcare professionals' advice may be subject to recall bias, especially if these were not salient experiences. Caution should be taken in generalising to other countries beyond Australia, as knowledge gaps and related concerns may be worse in countries where there is less focus on tobacco control. Researchers in other countries should replicate our study to understand local gaps in awareness and support, and preferences for cessation support.

Conclusion

Given the greater risks of smoking for people with MS, we should be placing greater effort into promoting and supporting initiatives for successful cessation in this group. Healthcare professionals and MS community support organisations are missing crucial opportunities to promote smoking cessation, thus not meeting the needs of people with MS. MS clinicians should take every opportunity to use evidence-based cessation tools as a priority in their practice. Regular assessment, advice and quit support tailored to people with MS may help to reduce the prevalence of smoking among people with MS, which is likely to improve health outcomes.

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Authors' contribution:

IWB: contributions to the design of the work, data acquisition, data analysis and interpretation, drafting the work and revising it critically for important intellectual content, final approval of the version to be published

LBG: Funding acquisition, methodology, writing – review and editing

RB: Funding acquisition, methodology, writing – review and editing

SLW: Was involved in data interpretation and critical revision of the article

RdN: Funding acquisition, methodology, writing – review and editing

CHM: Funding acquisition, methodology, project administration, resources, supervision, validation, writing – original draft, review and editing

Conflicts of interest:

RdN previously received funding for speakers' bureau from Biogen, Merck, and Novartis to deliver talks about cognition in MS. SLW is funded by Quit Victoria, with support from VicHealth, and manages the government-funded Quitline service in Victoria. LBG has received funding from Merck for an unrelated project.

Data availability

No additional data available.

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Tables

Table 1 Demographic and clinical information

	n	%
Total	284	100.0
Gender		
Women	250	88.0
Men	33	11.6
Non-conforming [a]	1	0.4
Age (years)		
18 - 29	26	9.2
30 - 39	64	22.5
40 - 49	79	27.8
50 - 64	95	33.5
65 and over	20	7.0
Education		
High school	66	23.2
Diploma or technical qualification	82	28.9
University degree	136	47.9
State of residence [b]		
New South Wales	68	24.0
Australian Capital Territory	12	4.2
Victoria	99	35.0
Queensland	25	8.8
South Australia	32	11.3
Western Australia	33	11.7
Tasmania	13	4.6
Northern Territory	1	0.4
Remoteness [c]		
Major Cities	204	72.3
Inner Regional	62	22.0
Outer Regional and remote	16	5.7
Main activity [b]		
Full-time employment	91	32.2
Part-time employment	69	24.4
Study, home or carer duties	32	11.3
Currently look for work, or other	21	7.4
Retirement	70	24.7
Disease duration [d]		
0-2 years	70	25.2
3-5 years	49	17.6
6-10 years	44	15.8
11-15 years	40	14.4
16 years or longer	75	27.0
MS subtype [d]		
Relapsing-remitting MS	211	75.9
Secondary progressive MS	40	14.4
Primary progressive MS	13	4.7
Other / unknown	14	5.0

Level of disability [d]		
No disability	81	29.1
Mild/moderate disability	91	32.7
Gait/cane disability	76	27.3
Bilateral support/Wheelchair /Scooter	30	10.8
Neurology care [e]		
Private neurologist	117	42.5
Public neurologist	151	54.9
Not regularly seeing a neurologist	7	2.5

[a] Text entry by participant. [b] Missing data n=1. [c] Missing data n=2. [d] Clinical variables include participants with definite MS only, no missing data. [e] Missing data=9.

Table 2. Awareness of associations between smoking and MS

		Don't know	More likely	Less likely	Makes no difference
Do you think people who smoke are more or less likely to get MS? [a]	n	113	68	0	99
	%	40.4	24.3	0	35.4
Do you think people who breathe in second-hand smoke are more or less likely to get MS? [b]	n	127	47	4	101
	%	45.5	16.8	1.4	36.2
Do you think that smoking has an impact on MS relapses? [b]	n	125	107	3	44
	%	44.8	38.4	1.1	15.8
Do you think that smoking has a long term impact on the progression of MS? [b]	n	133	116	0	30
	%	47.7	41.6	0	10.8
Do you think that smoking has an impact on MS medications? [c]	n	217	34	0	27
	%	78.1	12.2	0	9.7

[a] *n=280* [b] *n=279* [c] *n=278*

Table 3. Smoking habits, nicotine use and exposure to passive smoke

Variable	Respondents	Category	n	%
Smoking status	All participants	Current daily or weekly	73	25.7
		Former daily or weekly	108	38.0
		Never smoked daily or weekly	103	36.3
Using other nicotine products	All participants [a]	Yes	26	9.2
		No	257	90.8
Exposure to passive smoking	All participants [b]	Less than one day a week	215	76.2
		One day a week or more	67	23.8
Living with a current smoker	All participants [b]	Yes	49	17.4
		No	233	82.6
Age of smoking initiation	Current and former smokers [a]	12 - 17	105	58.3
		18 - 24	65	36.1
		25 - 33	10	5.6
Timing of quitting	Former smokers [a]	Quit before MS diagnosis	55	51.4
		Quit within year of diagnosis	15	14.0
		Quit 1 year or more after diagnosis	37	34.6
Number of quit attempts	Current smokers [b]	None	15	21.1

		1 - 5 times	40	56.3
		More than 5 times	14	19.7
		Don't remember	2	2.8
Average cigarettes per day	Current smokers [a]	1 - 5	10	13.9
		6 - 10	22	30.6
		11 - 20	31	43.1
		21 - 30	8	11.1
		31 - 40	1	1.4
Time after waking until first cigarette	Current smokers [a]	Less than 5 minutes	11	15.3
		5 - 30 minutes	36	50.0
		31 - 60 minutes	9	12.5
		After 60 minutes	16	22.2
Type of smoked tobacco	Current smokers [a]	Cigarettes only	64	88.9
		Cigarettes and other smoked tobacco	8	11.1

[a] n=1 missing data [b] n=2 missing data

Table 4 Short-term changes in symptoms or wellbeing immediately after smoking

	Better	**No change**	**Worse**	**Not applicable**
Symptoms	**n (%)**	**n (%)**	**n (%)**	**n (%)**
Pain	3 (4.3)	36 (51.4)	3 (4.3)	28 (40.0)
Stress	41 (58.6)	16 (22.9)	3 (4.3)	10 (14.3)
Anxiety	35 (50.0)	17 (24.3)	3 (4.3)	15 (21.4)
Depression	16 (22.9)	31 (44.3)	1 (1.4)	22 (31.4)
Fatigue/tiredness	5 (7.1)	43 (61.4)	9 (12.9)	13 (18.6)
Brain fog or alertness [a]	9 (13.0)	35 (50.7)	4 (5.8)	21 (30.4)
Bowel and/or bladder problems	4 (5.7)	40 (57.1)	4 (5.7)	22 (31.4)
Muscle spasms/spasticity	5 (7.1)	41 (58.6)	1 (1.4)	23 (32.9)
Sense of wellbeing	28 (40.0)	24 (34.3)	7 (10.0)	11 (15.7)

* Current smokers only (n=70), n=3 missing, [a] n=4 missing data

Table 5 Changes in symptoms or health after quitting for longer than 4 weeks

	Better	**No change or can't remember**	**Worse**	**Total***
Symptoms	**n (%)**	**n (%)**	**n (%)**	**n**
Pain	4 (18.2)	15 (68.2)	3 (13.6)	22
Stress	11 (37.9)	13 (44.8)	5 (17.2)	29
Anxiety	10 (35.7)	13 (46.4)	5 (17.9)	28
Depression	6 (23.1)	17 (65.4)	3 (11.5)	26
Fatigue/tiredness	12 (36.4)	17 (51.5)	4 (12.1)	33
Brain fog or alertness	7 (25.0)	18 (64.3)	3 (10.7)	28
Bowel and/or bladder problems	1 (3.8)	21 (80.8)	4 (15.4)	26
Muscle spasms/spasticity	8 (28.6)	19 (67.9)	1 (3.6)	28

Sense of wellbeing	28 (82.4)	3 (8.8)	3 (8.8)	34

*Only displayed to participants who had previously quit for longer than 4 weeks and reported some change in symptoms or health (n=41), instructed to only complete relevant items

Table 6. Smoking cessation support from healthcare providers

	Current smoker		Former smoker	
Current neurologist	**n**	**%**	**n**	**%**
Never asked	7	10.4	22	22.0
Asked once, no further information	19	28.4	41	41.0
Asked several times, no further information	6	9.0	8	8.0
Asked and advised to quit, no help	34	50.7	15	15.0
Asked, advised and provided help to quit	1	1.5	2	2.0
Can't remember	0	0.0	12	12.0
Total	67	100	100	100
Other healthcare providers*	**n**	**%**	**n**	**%**
Never asked	10	14.7	16	16.2
Asked once, no advice	16	23.5	21	21.2
Asked several times, no advice	3	4.4	5	5.1
Asked (no further information)	0	0.0	23	23.2
Asked and advised to quit, no help	25	36.8	18	18.2
Asked, advised, and provided help to quit	8	11.8	6	6.1
Can’t remember	6	8.8	10	10.1
Total	68	100	99	100

*examples provided in free text comments included general practitioner, dentist, physiotherapist, exercise physiologist, osteopath, speech therapist, psychologist, psychiatrist and occupational therapist. Help to quit could include provision of a script or referral to quit smoking service.

STROBE Statement—Checklist of items that should be included in reports of ***cross-sectional studies***

	Item No	Recommendation	Page No
Title and abstract	1	(*a*) Indicate the study's design with a commonly used term in the title or the abstract	1
		(*b*) Provide in the abstract an informative and balanced summary of what was done and what was found	1
Introduction			
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported	2-3
Objectives	3	State specific objectives, including any prespecified hypotheses	2-3
Methods			
Study design	4	Present key elements of study design early in the paper	3
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	3
Participants	6	(*a*) Give the eligibility criteria, and the sources and methods of selection of participants	3
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	3
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group	*3-4*
Bias	9	Describe any efforts to address potential sources of bias	4
Study size	10	Explain how the study size was arrived at	4
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	4
Statistical methods	12	(*a*) Describe all statistical methods, including those used to control for confounding	4
		(*b*) Describe any methods used to examine subgroups and interactions	4
		(*c*) Explain how missing data were addressed	4
		(*d*) If applicable, describe analytical methods taking account of sampling strategy	4
		(*e*) Describe any sensitivity analyses	N/a
Results			
Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed	4-5
		(b) Give reasons for non-participation at each stage	4
		(c) Consider use of a flow diagram	n/a
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders	4-5
		(b) Indicate number of participants with missing data for each variable of interest	4-5
Outcome data	15*	Report numbers of outcome events or summary measures	4-7
Main results	16	(*a*) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included	n/a

		(*b*) Report category boundaries when continuous variables were categorized	n/a
		(*c*) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	n/a
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses	n/a
Discussion			
Key results	18	Summarise key results with reference to study objectives	8-10
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias	11
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	11
Generalisability	21	Discuss the generalisability (external validity) of the study results	11
Other information			
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based	12

*Give information separately for exposed and unexposed groups.

Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at http://www.plosmedicine.org/, Annals of Internal Medicine at http://www.annals.org/, and Epidemiology at http://www.epidem.com/). Information on the STROBE Initiative is available at www.strobe-statement.org.

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Smoking habits, awareness, and support needs for cessation among people with multiple sclerosis in Australia: findings from an online survey

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Smoking habits, awareness, and support needs for cessation among people with multiple sclerosis in Australia: findings from an online survey

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Keywords: tobacco smoking, multiple sclerosis, health promotion, smoking cessation, clinical practice

Abstract

Objectives: To assess smoking habits, nicotine use, exposure to passive smoking, awareness of associated harms, and experiences with and preferences for smoking cessation support amongst people with multiple sclerosis (MS).

Design: Online survey, convenience sampling.

Setting: Community setting, Australia.

Participants: Adults living in Australia with probable or diagnosed MS were recruited via social media, and newsletters to participate in 2020.

Results: Of the 284 participants in our convenience sample, 25.7% were current smokers (n=73) and 38.0% were former smokers (n=108). Awareness of the harms of smoking on MS onset (n=68, 24.3%) and progression (n=116, 41.6%) was low. Almost a quarter (n=67, 23.8%) of participants were regularly exposed to passive smoke, and awareness of associated harm was also low (n=47, 16.8%). Among current smokers, 76.1% (n=54) had tried quitting and 73.2% considered quitting within 6 months (n=52). Many participants reported perceived short-term benefits of smoking, and long-term benefits of quitting, on MS symptoms and general wellbeing (short-term n=28, 40.0%; long-term n=28, 82.4%). While most participants reported that their neurologist (n=126, 75.4%) or other healthcare providers (n=125, 74.9%) had assessed smoking status, very few neurologists (n=3, 1.8%) or other healthcare providers (n=14, 8.4%) had provided help with quitting. Most current smokers preferred speaking about smoking to a neurologist (n=36, 52.2%) or general practitioner (n=41, 59.4%). Almost 60% of current smokers wanted additional cessation information specific to MS (n=41, 59.4%), and 45.5% said this information would motivate them to quit smoking (n=30).

Conclusions: Our convenience sample, which may not be representative, indicated an urgent need for regular evidence-based smoking cessation supports for people with MS. Most participants felt they would benefit from smoking cessation advice. MS clinicians, in collaboration with patient organisations, smoking cessation services, and general practitioners should make smoking cessation promotion with people with MS a priority.

Strengths and limitations of this study

- This study expands on perspectives of people with MS with relation to what and when smoking cessation information is provided, enabling targeted time-critical support.
- There is potential for bias related to self-selection in the study, which could lead to an overestimation of the prevalence of smoking, but underestimate the lack of knowledge about the relationship between MS and smoking.
- Furthermore, the lack of a prespecified target sample and the inability to calculate a response rate or assess non-response bias, due to the sampling method, limit the generalisability of the study.
- Reporting past quit attempts and healthcare professionals' advice may be subject to recall bias.
- Caution should be taken in generalising to other countries beyond Australia, as knowledge gaps and related concerns may be worse in countries where there is less focus on tobacco control.

Introduction

Current evidence indicates that genetic and environmental factors contribute to multiple sclerosis (MS) risk,[1] and tobacco smoking has been identified as a key modifiable risk factor.[2] Smoking tobacco presents considerable health risks to people diagnosed with MS,[3] with evidence for a causal association between smoking and MS progression.[4–6] Furthermore, studies in people with MS report associations between tobacco smoking and worse fatigue, depressive symptoms and health-related quality of life[7]; higher relapse rate during interferon beta treatment[8] and natalizumab treatment[9]; more co-morbidities such as heart disease[10]; and higher premature mortality.[11]

Evidence is emerging that people with MS are largely unaware of the risks of smoking to MS, and that there are MS-specific barriers to quitting, such as the potential impact of cessation-induced stress on MS. [12][13][14] Our qualitative work also identified several MS-specific barriers to smoking cessation, including concerns that quitting may negatively impact MS symptoms, such as mood, cognition, pain, and relapses. [14] Some participants were also unsure whether nicotine replacement therapy (NRT) or other cessation medications would be safe to use for people with MS, or in combination with common MS medication, an indication that needs of people with MS in relation to smoking cessation were not met. [14]

The current study aimed to assess whether people with MS (regardless of smoking status) were aware of the links between smoking, including passive smoking, and MS. Furthermore, we aimed to quantitatively assess smoking habits, motivators for smoking, barriers and facilitators to smoking cessation, and cessation preferences of people with MS who were current or former smokers. If there are MS-specific barriers to cessation, a lack of tailored support and information that goes beyond tools designed for the general population is likely to mean less successful cessation.[3]

Methods

Ethics approval, reporting standards, and pariticpant consent

This study was approved by the ethics committee at The University of Melbourne (HREC-1954916.3), and conforms to the STROBE guidelines for cross-sectional studies and the Checklist for Reporting Of Survey Studies (CROSS) (Supplementary files 1 and 2).[15,16] Participants provided digital consent before entering the survey. Responses were recorded confidentially in Qualtrics, and the data files stored in a password protected folder on a secure university server. Participant data were deidentified for analyses.

Participants and recruitment

People living in Australia aged 18 years and older with probable (neurologist-diagnosed clinically isolated syndrome or first demyelinating event) or diagnosed MS were invited to participate via websites, newsletters and social media channels of relevant organisations in Australia (MS Australia, MS Research Australia, and the MS state societies) and MS support groups. Data were collected over 11 weeks between May and July 2020.

Survey

The survey consisted of approximately 75 questions, with a mix of multiple-choice, matrix table and text entry questions, using display logic to direct participants to relevant questions consistent with previous responses using the platform Qualtrics (Supplementary file 3).

The survey collected demographic and clinical information including level of disability using the Patient Disability Disease Steps.[17] Remoteness of residential location was derived from postcodes.[18] Participants were asked about smoking habits, knowledge of and experience with smoking, passive smoking, smoking cessation, nicotine products, interactions with healthcare providers regarding smoking-related topics and preferences for smoking cessation support.

Data analysis

Stata/SE 16.1 was used for all analyses.[19] Descriptive statistics are presented for survey responses, stratified by smoking status when relevant. Median and interquartile range (IQR) were calculated for continuous variables that were not normally distributed. In some instances where several multiple-choice options were offered, categories were combined for presentation in the results. Integrity of the data was checked to identify and remove ineligible participants, bots (automatically flagged by Qualtrics), duplicate responses or mostly incomplete responses (less than 20% of survey items). We conducted a complete case analysis, and percentages were calculated based on the number of participants that completed that item, reported in each section.

Patient and public involvement

The survey instrument was constructed from the results of previous in-depth qualitative interviews assessing the perspectives of 25 people with MS who were current or recent smokers[20] and research team expertise, which included a person with MS, a former smoker, smoking cessation experts, MS researchers, clinicians, and cessation advocates. Some survey items were based on

other relevant surveys and literature.[21–24] Four volunteers not involved in the study pilot-tested the survey.

Results

After removing 29 records (n=1 bot; n=1 duplicate; n=2 did not consent to participate; n=3 did not have either definite or probable MS; n=22 exited survey before completing 20% of survey questions), the final convenience sample comprised 284 participants, 90.1% of whom completed all survey questions relevant to them (n=256).

Demographic and clinical information

Most participants were women (n=250, 88.0%), and the median age was 46 (IQR 38-56.5, range 18-76 years). Almost all participants reported a neurologist-confirmed diagnosis of definite MS (n=278, 97.9%) and median years since diagnosis was 7 years (IQR 2-16, range 0-39 years). Other characteristics are reported in Table 1.

Table 1. Demographic and clinical information

	n	%
Total	284	100.0
Gender		
Women	250	88.0
Men	33	11.6
Non-conforming [a]	1	0.4
Age (years)		
18 - 29	26	9.2
30 – 39	64	22.5
40 – 49	79	27.8
50 – 64	95	33.5
65 and over	20	7.0
Education		
High school	66	23.2
Diploma or technical qualification	82	28.9
University degree	136	47.9
State of residence [b]		
New South Wales	68	24.0
Australian Capital Territory	12	4.2
Victoria	99	35.0
Queensland	25	8.8
South Australia	32	11.3
Western Australia	33	11.7
Tasmania	13	4.6
Northern Territory	1	0.4
Remoteness [c]		

Major Cities	204	72.3
Inner Regional	62	22.0
Outer Regional and remote	16	5.7
Main activity [b]		
Full-time employment	91	32.2
Part-time employment	69	24.4
Study, home or carer duties	32	11.3
Currently look for work, or other	21	7.4
Retirement	70	24.7
Disease duration [d]		
0-2 years	70	25.2
3-5 years	49	17.6
6-10 years	44	15.8
11-15 years	40	14.4
16 years or longer	75	27.0
MS subtype [d]		
Relapsing-remitting MS	211	75.9
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Other / unknown	14	5.0
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[a] Text entry by participant. [b] Missing data n=1. [c] Missing data n=2. [d] Clinical variables include participants with definite MS only, no missing data. [e] Missing data=9.

Awareness of the relationship between smoking and MS

Most participants were unaware of the associations between smoking and MS onset, progression or treatment (Table 2). Those 150 participants who were aware of at least one of the risks were asked how they obtained this information. The most common sources for this information were MS healthcare providers (n=64, 42.7%), online information (n=54, 36.0%), MS societies (n=40, 26.7%), guessing (n=27, 18.0%), general practitioner (n=14, 9.3%), family member or friend (n=6, 4.0%), and other (n=19, 12.7%).

Table 2. Awareness of associations between smoking and MS

		Don't know	More likely	Less likely	Makes no difference
Do you think people who smoke are more or less likely	n	113	**68**	0	99

to get MS? [a]	%	40.4	**24.3**	0	35.4
Do you think people who breathe in second-hand smoke are more or less likely to get MS? [b]	n	127	47	4	101
	%	45.5	16.8	1.4	36.2
Do you think that smoking has an impact on MS relapses? [b]	n	125	107	3	44
	%	44.8	38.4	1.1	15.8
Do you think that smoking has a long term impact on the progression of MS? [b]	n	133	**116**	0	30
	%	47.7	**41.6**	0	10.8
Do you think that smoking has an impact on MS medications? [c]	n	217	34	0	27
	%	78.1	12.2	0	9.7

[a] *n=280* [b] *n=279* [c] *n=278*

Smoking habits and nicotine use

As reported in Table 3, 73 participants were current smokers (25.7%) (67 daily, 6 weekly) and 38.0% were former smokers (n=108). Use of nicotine vaping products (n=14, 7.8%) and NRT (n=12, 6.7%) was reported by 23.6% of current smokers (n=17) and 8.3% of former smokers (n=9), but none of the never smokers. Almost half of the current smokers (n=31, 43.7%) and 17.1% of non-smokers (n=36) reported being exposed to passive smoke regularly, while 10.0% of non-smokers (n=21) and 39.4% of smokers (n=28) lived with someone who smoked.

Of those (n= 43) current and former smokers who made a quit attempt in the past two years, less than half used NRT (n=20, 46.5%), while some used other stop-smoking medication (n=12, 27.9%), advice from healthcare provider (n=12, 27.9%), internet sites for quitting advice and support (n=10, 23.3%), or mobile phone-based programs (n=9, 20.9%). Only 18.6% indicated they quit without any cessation support (n=8). Most current smokers reported attempts to quit in the past (n=54, 76.1%), and 28.2% reported attempts to quit in the past 12 months (n=20). Quit attempts commonly lasted less than 1 month in duration (n=24, 44.4%).

Table 3. Smoking habits, nicotine use and exposure to passive smoke

Variable	Respondents	Category	n	%
Smoking status	All participants	Current daily or weekly	73	25.7
		Former daily or weekly	108	38.0
		Never smoked daily or weekly	103	36.3
Using other nicotine products	All participants [a]	Yes	26	9.2
		No	257	90.8
Exposure to passive smoking	All participants [b]	Less than one day a week	215	76.2
		One day a week or more	67	23.8
Living with a current smoker	All participants [b]	Yes	49	17.4
		No	233	82.6

Age of smoking initiation	Current and former smokers [a]	12 - 17	105	58.3
		18 - 24	65	36.1
		25 - 33	10	5.6
Timing of quitting	Former smokers [a]	Quit before MS diagnosis	55	51.4
		Quit within year of diagnosis	15	14.0
		Quit 1 year or more after diagnosis	37	34.6
Number of quit attempts	Current smokers [b]	None	15	21.1
		1 - 5 times	40	56.3
		More than 5 times	14	19.7
		Don't remember	2	2.8
Average cigarettes per day	Current smokers [a]	1 - 5	10	13.9
		6 - 10	22	30.6
		11 - 20	31	43.1
		21 - 30	8	11.1
		31 - 40	1	1.4
Time after waking until first cigarette	Current smokers [a]	Less than 5 minutes	11	15.3
		5 - 30 minutes	36	50.0
		31 - 60 minutes	9	12.5
		After 60 minutes	16	22.2
Type of smoked tobacco	Current smokers [a]	Cigarettes only	64	88.9
		Cigarettes and other smoked tobacco	8	11.1

[a] n=1 missing data [b] n=2 missing data

Motivators to continue smoking

Almost all current smokers (n=72, 1 missing) reported to smoke to cope with stress (n=51, 70.8%), to have time out/a break (n=44, 61.1%), for enjoyment (n=35, 48.6%), as a distraction (n=25, 34.7%), for something to do when their mood is low (n=25, 34.7%), and to prevent nicotine withdrawal symptoms (n=22, 30.6%). Some reported smoking for something to do when isolated (n=16, 22.2%), because their partner or other person in their household smokes (n=10, 13.9%), to cope with MS symptoms (n=9, 12.5%), or for something to do when unable to work (n=6, 8.3%).

Readiness and motivators to quit

Of 71 current smokers, 21.1% considered quitting in the next 30 days (n=15), and an additional 52.1% in the next 6 months (n=37). Their motivators to quit included to improve general health (n=50, 96.2%), MS or MS symptoms (n=30, 57.7%), for financial reasons (n=27, 51.9%), and for family, partner, and friends (n=17, 32.7%), and social pressure (n=7, 13.5%). Some current smokers were not seriously thinking of quitting in the next 6 months (n=10, 14.1%) and some were not at all interested in quitting (n=9, 12.7%).

Changes in symptoms and wellbeing from smoking or cessation

Current smokers were asked whether they noticed short-term changes in symptoms or wellbeing immediately after smoking, reported in Table 4. Of the 71 current smokers who reported concerns regarding smoking cessation, most cited negative effects on mood (n=43, 60.6%), and the process being too stressful (n=38, 53.5%) and difficult (scared they could not quit) (n=35, 49.3%), an increase in boredom (n=20, 28.2%), side effects of quitting medications (n=15, 21.1%), an MS relapse due to the stress of quitting (n=14, 19.7%), worsening of symptoms (n=10, 14.1%), and smoking cessation medications interfering with MS medication (n=10, 14.1%). Participants who had ever quit smoking for more than 4 weeks reported overall improvements in symptoms (Table 5).

Table 4. Short-term changes in symptoms or wellbeing immediately after smoking

	Better	No change	Worse	Not applicable
Symptoms	**n (%)**	**n (%)**	**n (%)**	**n (%)**
Pain	3 (4.3)	36 (51.4)	3 (4.3)	28 (40.0)
Stress	41 (58.6)	16 (22.9)	3 (4.3)	10 (14.3)
Anxiety	35 (50.0)	17 (24.3)	3 (4.3)	15 (21.4)
Depression	16 (22.9)	31 (44.3)	1 (1.4)	22 (31.4)
Fatigue/tiredness	5 (7.1)	43 (61.4)	9 (12.9)	13 (18.6)
Brain fog or alertness [a]	9 (13.0)	35 (50.7)	4 (5.8)	21 (30.4)
Bowel and/or bladder problems	4 (5.7)	40 (57.1)	4 (5.7)	22 (31.4)
Muscle spasms/spasticity	5 (7.1)	41 (58.6)	1 (1.4)	23 (32.9)
Sense of wellbeing	28 (40.0)	24 (34.3)	7 (10.0)	11 (15.7)

* Current smokers only (n=70), n=3 missing, [a] n=4 missing data

Table 5. Changes in symptoms or health after quitting for longer than 4 weeks

	Better	No change or can't remember	Worse	Total*
Symptoms	**n (%)**	**n (%)**	**n (%)**	**n**
Pain	4 (18.2)	15 (68.2)	3 (13.6)	22
Stress	11 (37.9)	13 (44.8)	5 (17.2)	29
Anxiety	10 (35.7)	13 (46.4)	5 (17.9)	28
Depression	6 (23.1)	17 (65.4)	3 (11.5)	26
Fatigue/tiredness	12 (36.4)	17 (51.5)	4 (12.1)	33
Brain fog or alertness	7 (25.0)	18 (64.3)	3 (10.7)	28
Bowel and/or bladder problems	1 (3.8)	21 (80.8)	4 (15.4)	26
Muscle spasms/spasticity	8 (28.6)	19 (67.9)	1 (3.6)	28
Sense of wellbeing	28 (82.4)	3 (8.8)	3 (8.8)	34

*Only displayed to participants who had previously quit for longer than 4 weeks and reported some change in symptoms or health (n=41), instructed to only complete relevant items

Healthcare providers and cessation support

Among current smokers with a current neurologist (n=67), only 1 participant reported that their neurologist had provided assessment, advice as well as support with quitting (Table 6). A lower proportion of current smokers reported that their private neurologist assessed their smoking status (n=21, 80.8%) and advised to quit (n=10, 38.5%), compared to those visiting public neurologists (asked about smoking status: n=39, 95.1%, advised to quit: n=25, 61.0%). Of current smokers with a neurologist, 77.6% reported that their neurologist was aware of their smoking status (n=52). Of current smokers who were seeing health professionals other than MS clinicians, 85.3% reported that their general practitioner was aware of their smoking status (n=58).

Of current and former smokers, 28.1% reported that they were satisfied with the cessation support that they received from their healthcare providers (n=47) (similar for current vs former smokers). More than one third of current smokers reported that they would feel disappointed if none of their healthcare providers discussed smoking with them (n=26, 38.2%), some would feel relieved (n=9, 13.2%), and the rest selected a neutral response (n=32, 47.1%).

Table 6. Smoking cessation support from healthcare providers

	Current smoker		Former smoker	
Current neurologist	**n**	**%**	**n**	**%**
Never asked	7	10.4	22	22.0
Asked once, no further information	19	28.4	41	41.0
Asked several times, no further information	6	9.0	8	8.0
Asked and advised to quit, no help	34	50.7	15	15.0
Asked, advised and provided help to quit	1	1.5	2	2.0
Can't remember	0	0.0	12	12.0
Total	67	100	100	100
Other healthcare providers*	**n**	**%**	**n**	**%**
Never asked	10	14.7	16	16.2
Asked once, no advice	16	23.5	21	21.2
Asked several times, no advice	3	4.4	5	5.1
Asked (no further information)	0	0.0	23	23.2
Asked and advised to quit, no help	25	36.8	18	18.2
Asked, advised, and provided help to quit	8	11.8	6	6.1
Can't remember	6	8.8	10	10.1
Total	68	100	99	100

*examples provided in free text comments included general practitioner, dentist, physiotherapist, exercise physiologist, osteopath, speech therapist, psychologist, psychiatrist and occupational therapist. Help to quit could include provision of a script or referral to quit smoking service.

Preferences for smoking cessation support

Most current smokers (n=69, 4 missing) reported a preference to speak about smoking with their general practitioner (n=41, 59.4%) or neurologist (n=36, 52.2%), with fewer mentioning an MS nurse (n=24, 34.8%) and a pharmacist (n=12, 17.4%). Only 5.8% preferred not to speak with any healthcare provider (n=4). Half of the current smokers ranked the importance of receiving cessation support from people with knowledge about MS as extremely or very important (n=34, 50.7%).

Of the current smokers, more than half reported that they need additional cessation information specific to MS (n=41, 59.4%) (regardless of readiness to quit). If current smokers were to receive information about the MS-related benefits of quitting, 45.5% reported they would be motivated to quit smoking (n=30) and an additional 19.7% would be motivated to reduce smoking (n=13). However, 19.7% reported that such information would not affect their smoking habits (n=13), and a small proportion expected that such information would elicit guilt and stress, causing them to smoke more (n=8, 12.1%). Current smokers were asked when they thought people with MS should be offered information about the benefits of quitting. Preferred times were at the time of diagnosis (n=27, 40.9%), within 1 month of diagnosis (n=16, 24.2%) and at a later time (n=15, 22.7%).

Importance of receiving cessation support from people with knowledge about MS

Just over half of 69 current smokers expressed interest in a special program for smokers who have MS (n=39, 56.5%) and NRT (n=35, 50.7%). Other cessation support of interest included stop-smoking medications (n=24, 34.8%), advice from their neurologist or MS nurse (n=22, 31.9%), face-to-face advice from a smoking cessation expert including counselling (n=21, 30.4%), advice from another doctor or healthcare provider (n=17, 24.6%), mobile-based programs such as phone apps (n=16, 23.2%), and a workbook with tips and exercises (n=16, 23.2%). Less than 15% showed interest in either hospital-based service (n=8, 11.6), web-based program (n=6, 8.7%), internet sites for quitting advice and support (n=6, 8.7%, information brochures and booklets (n=6, 8.7%), online support group (n=4, 5.8%) or telephone Quitline service (n=1, 1.4%). Only 8.7% stated that they did not want support for quitting (n=6). Topics that at least 75% of current and former smokers who quit after MS diagnosis thought were important for quit services to address included (in order of importance): Interactions of anti-smoking medication with MS medication (n=147, 91.3%), effect of stress due to quitting on MS relapses (n=145, 90.6%), temporary worsening of symptoms due to quitting (n=145, 90.6%), benefits of quitting on MS (n=142, 88.2%), effect on mood (n=139, 87.4%), challenges people with MS might face (137, 85.1%), side effects of anti-smoking medication (n=136, 84.5%),

withdrawal symptoms of quitting smoking (n=136, 84.5%), benefits of quitting on general health (n=130, 80.7%), effect on relationships (n=124, 77.0%), and weight gain (n=123, 76.4%).

Discussion

Our sample was similar to the Australian MS Longitudinal Study (AMSLS) cohort,[25–27] which has been validated as representative of the Australian MS population, [28] when comparing demographic variables including education level, state of residence, remoteness, employment status, MS subtype and level of disability. However, it is possible that younger people, women, and people with lower disease duration are over-represented in our sample (AMSLS women 77.7%[28] vs present sample 88.0%; AMSLS mean age (SD) 55.7 (11.2) vs present sample 46.7 (12.1); AMSLS mean disease duration (SD) 16.1 (11.2) vs present sample 10.4 (9.9)). Smoking prevalence is higher in our sample of Australian adults with MS (25.7% were current smokers, of which 23.6% daily smokers, and 38.0% former smokers in our sample) compared to the 2019 national average estimates for adults at 11.6% daily smokers and 24.3% former smokers.[29] Current smokers in our study were commonly long-time heavy smokers who had attempted to quit in the past. More than a quarter of current smokers (28.2%) had attempted to quit in the previous year (similar to 31% in the general population[29]) and the majority considered quitting in the next 6 months. Almost a quarter of all participants, including 17.1% of non-smokers, were regularly exposed to passive smoking, which may also increase the risk for poor health outcomes.

One of the top motivators for quitting was to improve MS and related symptoms, which indicated a general belief that smoking is harmful for MS. However, our results showed extremely low levels of awareness of adverse effects of smoking and passive smoking on MS onset, progression and treatment in our sample. This lack of knowledge of a modifiable risk factor represents a failing in caring for people with MS, and is consistent with other studies.[12,13] [14] There is an urgent need for remedial education and action to ensure better promotion of smoking cessation as an integral part of MS care. Since information about relevant health consequences contributes to the success of cessation interventions for other groups, better education should contribute to smoking cessation success as well as avoidance of passive smoke exposure in people with MS. [30]

Unsurprisingly, people with MS experience many of the same motivators to continue smoking as people in the general population, including stress-relief,[31] which is not surprising since nicotine causes an immediate sense of relaxation.[32] The reported motivators to cope with stress and low

mood may be more of an issue for people with MS since they experience higher levels of anxiety and depression than the general population.[33–35] When promoting smoking cessation, it needs to be acknowledged that many participants reported immediate benefits from smoking such as perceived well-being, which are likely major barriers to cessation attempts and success.

In the long-term however, more participants reported improved rather than worsened stress and anxiety after quitting for longer than 4 weeks. This is consistent with evidence that smoking is not an effective long-term strategy of dealing with stress and anxiety.[32,36] Reported improvements in sense of wellbeing and fatigue after quitting for longer than a month are also consistent with the literature.[37] Bladder and/or bowel problems was the only symptom group for which slightly more participants reported worsening rather than improvement after quitting, albeit most reported no change. Overall, these results strongly indicate that there is a need to support people with MS to find less harmful ways to maintain or enhance moment-to-moment well-being.

Australian guidelines state that smoking cessation should be a key component in chronic disease management.[38] However, less than 30% of current and former smokers in our study were satisfied with the cessation support that they received from their healthcare providers, consistent with our qualitative findings that the information and support needs of people with MS are often not met .[14] Even though most smokers reported that their neurologist had enquired about their smoking status, only half reported that their neurologist advised cessation, and only one participant reported that their neurologist provided support to quit, such as pharmacotherapy or referral to a cessation service. Further, less than one third of current and former smokers who quit in the past two years received support from a healthcare professional. The Australian guidelines for smoking cessation recommend the use of NRT or stop-smoking medications,[38] which generally increase cessation success by 50-60%[39]; however, less than half of the current and former smokers who quit in the past two years used NRT and less than one third used smoking cessation medications. These findings are consistent with those from the Australian general population, showing that people more commonly attempt to quit ‘cold turkey’, rather than using NRT or medication, or advice from a healthcare provider[29].

Our findings indicating inadequate support for smoking cessation, coupled with the poor awareness of smoking risks, indicates that critical opportunities to educate about smoking and promote cessation are missed. This gap in MS healthcare is mirrored in the management of other smoking-related diseases, such as in cancer management by oncologists in Australia.[40]

Implications for practice

Health providers should be supported to follow evidence-based guidelines for promoting smoking cessation, including regularly assess smoking status, providing information and advice about the benefits of quitting on general health and MS, as well as smoking cessation support[38] to people with, or at risk for, MS who smoke and are interested in quitting.[3,41] A major focus of support should be on finding ways to help people with MS to manage their well-being without smoking; this is likely a more salient issue for them than for smokers in the general population.

Depending on the clinicians' capabilities and resources, providing cessation support might include referrals to smoking cessation services, counselling services specialised in behaviour change, prescribing NRT and/or other smoking cessation medications, and arranging extra support with symptom management. Further, smoking cessation services likely need to improve their understanding of concerns related to MS-specific barriers to smoking cessation, including potential management of mood disorders and other MS-related symptoms, which might temporarily worsen. Many participants were interested in a program for people with MS who smoke, and tailored approaches to cessation support have proven helpful in other populations such as pregnant women and cancer patients.[30,42] While general practitioners may be better placed to spend time providing smoking management on a regular basis, MS clinicians may also have an important role in promoting smoking cessation and communicating its importance in relation to MS.[14] Information provision is particularly important around the time of diagnosis, which is a time when people with MS may be most motivated to make behavioural changes,[14] in line with literature on the so-called "teachable moment". However, continuing support will be needed for those unable to make or sustain such a change in the stressful period following diagnosis, and to prevent smoking relapse among those initially successful.

Research is needed to understand whether collaborative efforts from the MS community (MS clinicians, patient advocates, allied health professionals) with GPs and smoking cessation experts increases cessation success in people with MS over time.

Strengths and limitations

To our knowledge, this is the first survey to assess variables related to tobacco smoking in Australian people with MS. The main limitation is the potential for bias related to self-selection into the study, with those who smoke, but perhaps not those self-conscious that they smoke, and those more

interested in smoking cessation more likely to participate. This could lead to an overestimation of prevalence of smoking. However, if our assumptions are correct, it might, as indicated above, underestimate lack of knowledge about the relationship between MS and smoking. Furthermore, the lack of a prespecified target sample and the inability to calculate a response rate or assess non-response bias, due to the sampling method, limit the generalisability of the study. As a result, the prevalence estimates should be treated as indicative rather than precise. We also recognise that reporting past quit attempts and healthcare professionals' advice may be subject to recall bias, especially if these were not salient experiences. Caution should be taken in generalising to the Australian MS community; as well as other countries beyond Australia, as knowledge gaps and related concerns may be worse in countries where there is less focus on tobacco control. Researchers in other countries should replicate our study to understand local gaps in awareness and support, and preferences for cessation support. Finally, we did not collect survey data in people without MS, which could have elucidated differences in smoking cessation experiences, knowledge and barriers between people with and without MS.

Conclusion

Given the greater risks of smoking for people with MS, we should be placing greater effort into promoting and supporting initiatives for successful cessation in this group. Healthcare professionals and MS community support organisations are missing crucial opportunities to promote smoking cessation, thus not meeting the needs of people with MS. MS clinicians should take every opportunity to use evidence-based cessation tools as a priority in their practice. Regular assessment, advice and quit support tailored to people with MS may help to reduce the prevalence of smoking among people with MS, which is likely to improve health outcomes.

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Contributors

IWB: contributions to the design of the work, data acquisition, data analysis and interpretation, drafting the work and revising it critically for important intellectual content, final approval of the version to be published.

LBG: Funding acquisition, methodology, writing – review and editing.

RB: Funding acquisition, methodology, writing – review and editing.

SLW: Was involved in data interpretation and critical revision of the article.

RdN: Funding acquisition, methodology, writing – review and editing.

CHM: Funding acquisition, methodology, project administration, resources, supervision, validation, writing – original draft, review and editing.

Competing interests

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Data availability statement

No additional data are available.

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Supplementary file 1. STROBE Statement—Checklist of items that should be included in reports of ***cross-sectional studies***

	Item No	Recommendation	Page No
Title and abstract	1	(*a*) Indicate the study's design with a commonly used term in the title or the abstract	1-2
		(*b*) Provide in the abstract an informative and balanced summary of what was done and what was found	2
Introduction			
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported	4
Objectives	3	State specific objectives, including any prespecified hypotheses	4
Methods			
Study design	4	Present key elements of study design early in the paper	4
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	5
Participants	6	(*a*) Give the eligibility criteria, and the sources and methods of selection of participants	5
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	5
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group	5
Bias	9	Describe any efforts to address potential sources of bias	12
Study size	10	Explain how the study size was arrived at	6
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	5
Statistical methods	12	(*a*) Describe all statistical methods, including those used to control for confounding	5
		(*b*) Describe any methods used to examine subgroups and interactions	5
		(*c*) Explain how missing data were addressed	5
		(*d*) If applicable, describe analytical methods taking account of sampling strategy	NA
		(*e*) Describe any sensitivity analyses	NA
Results			
Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed	6-9, Tables 1-6
		(b) Give reasons for non-participation at each stage	NA
		(c) Consider use of a flow diagram	NA
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders	6, Table 1
		(b) Indicate number of participants with missing data for each variable of interest	6-9, Tables 1-6

Outcome data	15*	Report numbers of outcome events or summary measures	6-9, Tables 1-6
Main results	16	(*a*) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included	NA
		(*b*) Report category boundaries when continuous variables were categorized	NA
		(*c*) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	NA
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses	NA
Discussion			
Key results	18	Summarise key results with reference to study objectives	9-11
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias	12
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	11-13
Generalisability	21	Discuss the generalisability (external validity) of the study results	12
Other information			
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based	13

*Give information separately for exposed and unexposed groups.

Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at http://www.plosmedicine.org/, Annals of Internal Medicine at http://www.annals.org/, and Epidemiology at http://www.epidem.com/). Information on the STROBE Initiative is available at www.strobe-statement.org.

Supplementary file 2. Checklist for Reporting Of Survey Studies (CROSS)

Section/topic	Item	Item description	Reported on page #
Title and abstract			
Title and abstract	1a	State the word "survey" along with a commonly used term in title or abstract to introduce the study's design.	1-2
	1b	Provide an informative summary in the abstract, covering background, objectives, methods, findings/results, interpretation/discussion, and conclusions.	2
Introduction			
Background	2	Provide a background about the rationale of study, what has been previously done, and why this survey is needed.	4
Purpose/aim	3	Identify specific purposes, aims, goals, or objectives of the study.	4
Methods			
Study design	4	Specify the study design in the methods section with a commonly used term (e.g., cross-sectional or longitudinal).	4
Data collection methods	5a	Describe the questionnaire (e.g., number of sections, number of questions, number and names of instruments used).	5
	5b	Describe all questionnaire instruments that were used in the survey to measure particular concepts. Report target population, reported validity and reliability information, scoring/classification procedure, and reference links (if any).	5
	5c	Provide information on pretesting of the questionnaire, if performed (in the article or in an online supplement). Report the method of pretesting, number of times questionnaire was pre-tested, number and demographics of participants used for pretesting, and the level of similarity of demographics between pre-testing participants and sample population.	5
	5d	Questionnaire if possible, should be fully provided (in the article, or as appendices or as an online supplement).	Supp. 3
Sample characteristics	6a	Describe the study population (i.e., background, locations, eligibility criteria for participant inclusion in survey, exclusion criteria).	5
	6b	Describe the sampling techniques used (e.g., single stage or multistage sampling, simple random sampling, stratified sampling, cluster sampling, convenience sampling). Specify the locations of sample participants whenever clustered sampling was applied.	5
	6c	Provide information on sample size, along with details of sample size calculation.	6
	6d	Describe how representative the sample is of the study population (or target population if possible), particularly for population-based surveys.	9
Survey	7a	Provide information on modes of questionnaire administration, including the type and number of contacts, the location where the survey was conducted (e.g., outpatient	5

administration		room or by use of online tools, such as SurveyMonkey).	
	7b	Provide information of survey's time frame, such as periods of recruitment, exposure, and follow-up days.	5
	7c	Provide information on the entry process: –>For non-web-based surveys, provide approaches to minimize human error in data entry. –>For web-based surveys, provide approaches to prevent "multiple participation" of participants.	5
Study preparation	8	Describe any preparation process before conducting the survey (e.g., interviewers' training process, advertising the survey).	5
Ethical considerations	9a	Provide information on ethical approval for the survey if obtained, including informed consent, institutional review board [IRB] approval, Helsinki declaration, and good clinical practice [GCP] declaration (as appropriate).	4
	9b	Provide information about survey anonymity and confidentiality and describe what mechanisms were used to protect unauthorized access.	4
Statistical analysis	10a	Describe statistical methods and analytical approach. Report the statistical software that was used for data analysis.	5
	10b	Report any modification of variables used in the analysis, along with reference (if available).	NA
	10c	Report details about how missing data was handled. Include rate of missing items, missing data mechanism (i.e., missing completely at random [MCAR], missing at random [MAR] or missing not at random [MNAR]) and methods used to deal with missing data (e.g., multiple imputation).	5-9, tables
	10d	State how non-response error was addressed.	12
	10e	For longitudinal surveys, state how loss to follow-up was addressed.	NA
	10f	Indicate whether any methods such as weighting of items or propensity scores have been used to adjust for non-representativeness of the sample.	NA
	10g	Describe any sensitivity analysis conducted.	NA
Results			
Respondent characteristics	11a	Report numbers of individuals at each stage of the study. Consider using a flow diagram, if possible.	6-9
	11b	Provide reasons for non-participation at each stage, if possible.	NA
	11c	Report response rate, present the definition of response rate or the formula used to calculate response rate.	NA

Descriptive results	11d	Provide information to define how unique visitors are determined. Report number of unique visitors along with relevant proportions (e.g., view proportion, participation proportion, completion proportion).	6
	12	Provide characteristics of study participants, as well as information on potential confounders and assessed outcomes.	6, Table 1
Main findings	13a	Give unadjusted estimates and, if applicable, confounder-adjusted estimates along with 95% confidence intervals and p-values.	NA
	13b	For multivariable analysis, provide information on the model building process, model fit statistics, and model assumptions (as appropriate).	NA
	13c	Provide details about any sensitivity analysis performed. If there are considerable amount of missing data, report sensitivity analyses comparing the results of complete cases with that of the imputed dataset (if possible).	NA
Discussion			
Limitations	14	Discuss the limitations of the study, considering sources of potential biases and imprecisions, such as non-representativeness of sample, study design, important uncontrolled confounders.	12
Interpretations	15	Give a cautious overall interpretation of results, based on potential biases and imprecisions and suggest areas for future research.	13
Generalizability	16	Discuss the external validity of the results.	12
Other sections			
Role of funding source	17	State whether any funding organization has had any roles in the survey's design, implementation, and analysis.	13
Conflict of interest	18	Declare any potential conflict of interest.	13
Acknowledgements	19	Provide names of organizations/persons that are acknowledged along with their contribution to the research.	13

Supplementary file 3. Survey

Please not, text in square brackets were not included in the survey, but are technical details about the question type. First line starting with slash indicates question logic. MC=multiple choice.

1.0	DEMOGRAPHIC INFORMATION
1.1	/ASK ALL/ Have you been diagnosed with multiple sclerosis (MS) by a neurologist? [Single answer multipe choice (MC), force response] a. Yes b. No but I have had a consultation with a neurologist and been given a probable diagnosis of MS (also known as a first demyelinating event or clinically isolated syndrome (CIS)) c. No
1.2	/ASK ALL/ What is your age? [Text entry, force response] _____ years
1.3	/ASK ALL/ What is your gender? [Single answer MC] a. Female b. Male c. Non-binary d. Prefer not to say
1.4	/ASK ALL/ What is the highest level of education you have completed? [Single answer MC] a. Year 11 or less b. Year 12 or equivalent c. College, associate diploma or TAFE d. Undergraduate, bachelor's e. Postgraduate, master's or doctorate
1.5	/ASK ALL/ Please enter your postcode. [Text entry]
1.6	/ASK ALL/ Which best describes how you spend most of your time? ⓘ Employment includes paid work as an employee or self-employed person, and paid leave such as parental leave. This excludes unpaid domestic work and volunteer work. [Single answer MC]

	a. Full time employment (usually working 35 or more hours per week) b. Part time employment (usually working less than 35 hours per week) c. Study d. Home or carer duties e. Currently looking for work f. Retirement g. Other_____
2.0	CLINICAL INFORMATION
2.1	/ASK if Q1.1 a or b is selected: DIAGNOSED MS or PROBABLE MS/ What date were you first diagnosed with MS or probable MS? ⓘ If you can't remember or estimate the month of diagnosis, leave the month blank and fill in the year. [Dropdown list] Month: ___ Year: ____
2.2	/ASK if Q1.1 a is selected: DIAGNOSED WITH MS/ What MS subtype are you now diagnosed with? [Single answer MC] a. Relapsing-remitting MS b. Secondary progressive MS c. Primary progressive MS d. Progressive relapsing MS e. Other (please state your subtype) ____ f. Unknown
2.3	/ASK if Q1.1 a is selected: DIAGNOSED WITH MS/ Patient Determined Disease Steps Please note that the following scale may not reflect your experience with MS and you may never experience these symptoms. Select the description that BEST describes your MS. [Single answer MC] **No Disability**: I may have some mild symptoms, mostly sensory due to MS but they do not limit my activity. If I do have an attack, I return to normal when the attack has passed. **Mild Disability**: I have some noticeable symptoms from MS, but they are minor and have only a small effect on my lifestyle. **Moderate Disability**: I don't have any limitations in my walking ability. However, I do have significant problems due to MS that limit daily activities in other ways. **Gait Disability**: MS does interfere with my activities, especially my walking. I can work a full day, but athletic or physically demanding activities are more difficult than they used to be. I usually don't need a cane or other assistance to walk, but I might need some assistance during an attack. **Early Cane / Walking stick**: I use a cane, walking stick or a single crutch or some other form of support (such as touching a wall or leaning on someone's arm) for walking all the time or part of the time,

	especially when walking outside. I think I can walk 7.6 metres / 25 feet in 20 seconds without a cane or crutch. I always need some assistance (cane or crutch) if I want to walk as far as 3 blocks. **Late Cane / Walking stick**: To be able to walk 7.6 metres / 25 feet, I have to have a cane, crutch or someone to hold onto. I can get around the house or other buildings by holding onto furniture or touching the walls for support. I may use a scooter or wheelchair if I want to go greater distances. **Bilateral Support**: To be able to walk as far as 7.6 metres / 25 feet I must have 2 canes or crutches or a walker. I may use a scooter or wheelchair for longer distances. **Wheelchair / Scooter**: My main form of mobility is a wheelchair. I may be able to stand and/or take one or two steps, but I can't walk 7.6 metres / 25 feet, even with crutches or a walker **Bedridden**: Unable to sit in a wheelchair for more than one hour.
3.0	SMOKING INFORMATION
3.1	/ASK ALL/ How often do you currently smoke cigarettes, cigars, pipes, or any other tobacco products? [Single answer MC, force response] a. Daily or nearly every day b. At least weekly but not every day c. Less often than weekly d. Not at all /a or b = current smoker; c or d = go to Q3.2/
3.2	/ASK if Q3.1 c or d is selected/ In the past, have you ever been a daily or weekly smoker of cigarettes, cigars, pipes, or any other tobacco products? [Single answer MC, force response] a. Daily b. Never daily, only weekly c. Never smoked regularly d. Never smoked at all /a or b = former smoker; c and d = never smoker/
3.3	/ASK if Q3.1 a or b is selected: CURRENT SMOKERS/ /ASK if Q3.2 a or b is selected: FORMER SMOKERS/ How old were you when you first started smoking cigarettes regularly? ⓘ Regularly = at least weekly. [Text entry, force response] ____ years

3.4	/ASK if Q3.1 a or b is selected: CURRENT SMOKERS/ What do you smoke? ⓘ 'Other smoked tobacco' includes cigars, cigarillos, filtered little cigars, pipes, water pipes, and hookahs [Single answer MC] a. Cigarettes only b. Cigarettes and other smoked tobacco c. Only other forms of smoked tobacco
3.5	/ASK if Q3.1 a or b is selected: CURRENT SMOKERS/ On the days that you smoke, how many cigarettes do you smoke on average per day? [Dropdown list] a. 1-5 b. 6-10 c. 11-20 d. 21-30 e. 31-40 f. More than 40
3.6	/ASK if Q3.1 a or b is selected: CURRENT SMOKERS/ On the days that you smoke, how soon after waking do you usually smoke your first cigarette? [Single answer MC] a. Within 5 minutes b. 5-30 minutes c. 31-60 minutes d. After 60 minutes
3.7	/ASK if Q3.1 a or b is selected: CURRENT SMOKERS/ Why do you smoke? Select all that apply. [Multiple answer MC] a. For enjoyment b. As a way of having time out c. As a distraction d. To cope with stress e. To cope with MS symptoms f. To prevent nicotine withdrawal symptoms g. Because my partner or other person in my household smokes h. Something to do when I am isolated i. Something to do when I am unable to work j. Something to do when my mood is low k. Other _____
3.8	/ASK ALL/ Do you currently use any other nicotine products daily or close to daily? Select all that apply. [Multiple answer MC] a. None

	b. Nicotine vaping products such as e-cigarettes c. Oral tobacco such as chewing tobacco or snuff (I.e. powdered tobacco) d. Nicotine gum e. Nicotine lozenges/tablets f. Nicotine inhaler g. Nicotine nasal spray h. Nicotine patch i. Nicotine mouth spray j. Other ____
3.9	/ASK ALL/ During the past 7 days, on how many days did you breathe second-hand smoke at home, at your workplace, or in a vehicle from someone other than you who was smoking tobacco? ⓘ Second-hand smoke is considered smoke that is passively inhaled from cigarettes smoked by other people. [Dropdown list] 0 days, 1 day, 2 days, 3 days, 4 days, 5 days, 6 days, 7 days
3.10	/ASK ALL/ Do you live with a smoker? [Single answer MC] a. Yes b. No
4.0	EXPERIENCES WITH QUITTING
4.1	/ASK if Q3.1 a or b is selected: CURRENT SMOKERS/ Which best describes your readiness to quit smoking? [Single answer MC, force response] a. Not at all interested in quitting b. Not seriously thinking of quitting in the next 6 months c. Considering quitting in the next 6 months d. Planning to quit in the next 30 days /a and b = not ready (precontemplation); c = unsure (contemplation); d = ready (preparation)/
4.2	/ASK if Q4.1 c or d is selected: CURRENT SMOKERS WHO ARE UNSURE OR READY TO QUIT/ Why are you thinking of quitting? Select all that apply. [Multiple answer MC] a. To improve my general health b. To improve my MS or MS symptoms c. For my partner d. For my family or friends e. For the environment f. Financial reasons g. Social pressure h. Other _____

4.3	/ASK if Q3.1 a or b is selected: CURRENT SMOKERS/ In the past, have you attempted to quit smoking? ⓘ Please note that this does not include 'cutting down' on smoking. Quit attempts may involve the use of other nicotine products such as nicotine patches. [Single answer MC, force response] a. Yes b. No c. Can't remember
4.4	/ASK if Q4.3 a is selected: CURRENT SMOKERS WHO HAVE ATTEMPTED TO QUIT/ Approximately how many times have you attempted to quit smoking in your life? [Single answer MC] a. 1-5 times b. 6-15 times c. 16-30 times d. More than 30 times
4.5	/ASK if Q4.3 a is selected: CURRENT SMOKERS WHO HAVE ATTEMPTED TO QUIT/ How long ago did your last quit attempt end? [Dropdown list, force response] a. 1 to 6 days ago b. 1 week to less than 2 weeks ago c. 2 weeks to less than 4 weeks ago d. 1 month to less than 3 months ago e. 3 months to less than 6 months ago f. 6 months to less than 9 months ago g. 9 months to less than 12 months ago h. 1 year to less than 2 years ago i. 2 to 5 years ago j. More than 5 years ago
4.6	/ASK if Q4.3 a is selected: CURRENT SMOKERS WHO HAVE ATTEMPTED TO QUIT/ How long did you stop smoking for the last time you attempted to quit? [Dropdown list] a. Less than 1 day b. 1 day to less than 2 weeks c. 2 weeks to less than 4 weeks d. 1 month to less than 3 months e. 3 months to less than 6 months f. 6 months to less than 9 months g. 9 months to less than 12 months h. 1 to 5 years i. More than 5 years
4.7	/ASK if Q3.1 a or b is selected: CURRENT SMOKERS/ What concerns do you have when you think about quitting? Select all that apply.

	[Multiple answer MC] a. Scared I can't do it/ Too hard b. Too stressful c. My partner or another family member smokes too, and they are not supportive of me quitting d. Negative effects on my relationships e. Negative effects on my mood (for example, anxiety or depression) f. Increase in boredom g. Worsening of my symptoms (for example, pain or brain fog) h. An MS relapse due to the stress of quitting i. Side effects of nicotine replacement therapy (e.g. nicotine patches and chewing gum) j. Side effects of quitting medications (e.g. Champix) k. If I use medication to help me quit it might interfere with my MS medication l. Other _____
4.8	/ASK if Q3.2 a or b is selected: FORMER SMOKERS/ Did you quit smoking before or after you were diagnosed? [Single answer MC] a. Before b. Around the time of diagnosis c. Within 1 year of diagnosis d. 1 year or longer after diagnosis e. Can't remember /a = quit before diagnosis; b = quit at time of diagnosis; c-d = quit after diagnosis; e = can't remember/
4.9	/ASK if Q3.2 a or b is selected: FORMER SMOKERS/ How long ago did you quit smoking? [Single answer MC, force response] a. Less than 6 months ago b. 6 months to less than 1 year ago c. 1 year to less than 2 years ago d. 2 to 5 years ago e. More than 5 years ago /readiness to change: a = action; b-e= maintenance/
4.10	/ASK if Q4.5 a-h is selected: CURRENT SMOKERS WHO'S MOST RECENT QUIT ATTEMPT ENDED LESS THAN 2 YEARS AGO/ /ASK if Q4.9 a-c is selected: FORMER SMOKERS WHO QUIT LESS THAN 2 YEARS AGO/ Please indicate which supports for quitting you have used in the past 2 years. Select all that apply. [Multiple answer MC] a. Nicotine replacement therapy products (e.g. nicotine patches, chewing gum). Please list which products____ b. Stop-smoking medications such as varenicline (also known as Champix) or bupropion (also known as Zyban) c. Advice from a doctor or healthcare provider d. Face-to-face advice from a smoking cessation expert, including counselling e. Telephone Quitline service f. Hospital-based service g. Mobile-based programs such as phone apps

	h. Web-based program i. Internet sites for quitting advice and support j. Online support group k. Self-help materials such as brochures and books l. Other _____ m. I did it without any help
5.0	KNOWLEDGE ABOUT THE LINK BETWEEN SMOKING AND MS
5.1	/ASK ALL/ Do you think people who smoke are more or less likely to get MS? [Single answer MC] a. Don't know b. More likely c. Less likely d. Neither, smoking makes no difference
5.2	/ASK ALL/ Do you think people who are often breathe in second-hand smoke are more or less likely to get MS? [Single answer MC] a. Don't know b. More likely c. Less likely d. Neither, smoking makes no difference
5.3	/ASK ALL/ Do you think that smoking has an impact on MS relapses? [Single answer MC] ⓘ A relapse is also known as an attack or flare-up. It is the occurrence of new symptoms or the worsening of old symptoms. a. Don't know b. Yes, smoking increases your chance of relapses c. Yes, smoking decreases your chance of relapses d. No, smoking does NOT impact relapse
5.4	/ASK ALL/ Do you think that smoking has a long term impact on the progression of MS? [Single answer MC] a. Don't know b. Yes, smoking speeds up MS progression c. Yes, smoking slows down MS progression d. No, smoking does NOT impact MS progression
5.5	/ASK ALL/ Do you think that smoking has an impact on MS medications? ⓘ MS medications refer to disease modifying therapies (DMTs). These may include Avonex®, Rebif®, Betaferon®, Plegridy® (beta interferons), Copaxone® (glatiramer acetate), Gilenya® (fingolimod),

	Aubagio® (teriflunomide), Tecfidera® (dimethyl fumarate), Mavenclad® (cladribine), Lemtrada® (alemtuzumab), Tysabri® (natalizumab), and Ocrevus® (ocrelizumab). [Single answer MC] a. Don't know b. Yes, smoking makes MS medications less effective c. Yes, smoking makes MS medications more effective d. No, smoking does NOT impact MS medications
5.6	/ASK if any Q5.1-Q5.5 b is selected: THOSE WHO KNOW SMOKING IS HARMFUL/ Approximately when did you find out that smoking is harmful for MS? [Single answer MC] a. Before I was diagnosed b. Within 1 year of diagnosis c. 1 to 5 years after diagnosis d. More than 5 years after diagnosis e. Can't remember
5.8	/ASK if any Q5.1-Q5.5 b is selected: THOSE WHO KNOW SMOKING IS HARMFUL/ How did you find out that smoking is harmful for MS? Select all that apply. [Multiple answer MC] a. I'm just guessing b. I found information online c. I was told by my general practitioner d. I was told by my MS healthcare provider (e.g. neurologist, MS nurse) e. Information from my MS society f. I was told by a friend or family member g. Other____
6.0	PERCEIVED EFFECT OF SMOKING AND SMOKING CESSATION
6.1	/ASK if Q3.1 a or b is selected: CURRENT SMOKERS/ Please indicate any short-term changes in symptoms or health issues that you experience immediately after having a cigarette. ⓘ Select 'not applicable' for symptoms you do NOT experience. [Matrix table] [gets better, no change, gets worse, not applicable] a. Pain b. Stress c. Anxiety d. Depression e. Fatigue/tiredness f. Brain fog or alertness g. Bowel and/or bladder problems h. Muscle spasms/spasticity i. Sense of wellbeing j. Other ____
	/ASK if Q3.2 a or b is selected: FORMER SMOKERS/

	Please indicate any short-term changes in symptoms or health issues that you used to experience immediately after having a cigarette. ⓘ Select 'not applicable' for symptoms you did NOT used to experience. [Matrix table] [got better, no change, got worse, not applicable, can't remember] a. Pain b. Stress c. Anxiety d. Depression e. Fatigue/tiredness f. Brain fog or alertness g. Bowel and/or bladder problems h. Muscle spasms/spasticity i. Sense of wellbeing j. Other ____
6.2	/ASK if Q4.3 a is selected: CURRENT SMOKERS WHO HAVE ATTEMPTED TO QUIT/ /ASK if Q3.2 a or b is selected: FORMER SMOKERS/ We are interested in your experiences of the LONG-TERM effects of quitting smoking. If you have ever quit smoking for longer than a 4 week period, did you notice any changes in symptoms or health issues? [Single answer MC] a. Yes b. No c. Can't remember d. Have never quit smoking for longer than 4 weeks
6.3	/ASK if Q6.2 a is selected: EVER SMOKERS WITH CHANGES IN SYMPTOMS AFTER QUITTING/ Please indicate any long-term changes in symptoms or health issues that you experienced after quitting longer than 4 weeks. Select 'not applicable' for symptoms you did NOT experience. [Matrix table] [got better, no change, got worse, not applicable, can't remember] a. Pain b. Stress c. Anxiety d. Depression e. Fatigue/tiredness f. Brain fog or alertness g. Bowel and/or bladder problems h. Muscle spasms/spasticity i. Sense of wellbeing j. Other ____
7.0	QUESTIONS RELATED TO HEALTHCARE PROVIDERS
7.1	/ASK ALL/ Do you see a neurologist for management of MS? [Single answer MC]

	a. Yes, a private neurologist b. Yes, a public neurologist c. No, I don't see a neurologist
7.2	/ASK if Q7.1 a or b is selected: THOSE WHO SEE A NEUROLOGIST/ Has your current neurologist ever asked you about smoking? [Single answer MC] a) Never asked b) Asked once, nothing more c) Asked several times, nothing more d) Asked and recommended quitting, but not strongly e) Asked and advised strongly to quit f) Asked, advised and provided help to quit (e.g. provision of a script or referral to a quit smoking service) g) Can't remember
7.3	/ASK ALL/ Have you seen an MS nurse for management of MS in the past two years? [Single answer MC] a. Yes, a private MS nurse b. Yes, a public MS nurse c. No, I haven't seen an MS nurse
7.4	/ASK if Q7.3 a or b is selected: THOSE WHO HAVE SEEN AN MS NURSE/ Has an MS nurse ever asked you about smoking? [Single answer MC] a) Never asked b) Asked once, nothing more c) Asked several times, nothing more d) Asked and recommended quitting, but not strongly e) Asked and advised strongly to quit f) Asked, advised and provided help to quit (e.g. provision of a script or referral to a quit smoking service) g) Can't remember
7.5	/ASK ALL/ Have any of your other healthcare providers asked you about your smoking status? [Single answer MC] a. Yes. Please list all (e.g. general practitioner, physiotherapist, etc.): _____ b. No, never c. Can't remember d. I don't see any other healthcare providers
7.6	/ASK if Q7.5 a is selected: THOSE WHO HAVE BEEN ASKED ABOUT SMOKING BY ANY OTHER HEALTHCARE PROVIDER/ Have they also advised you to quit smoking? [Single answer MC]

	a. One or more of them have asked once, nothing more b. One or more of them have asked several times, nothing more c. One or more of them have asked and recommended quitting, but not strongly d. One or more of them have asked and advised strongly to quit e. One or more of them have asked, advised and provided help to quit (e.g. provision of a script or referral to a quit smoking service) f. Can't remember
7.7	/ASK if Q3.1 a or b is selected AND Q7.1 c, Q7.3 c or Q7.5 d is not selected: CURRENT SMOKERS WHO SEE AT LEAST ONE HEALTHCARE PROVIDER/ /* Display if Q7.1 c is not selected/ /** Display if Q7.3 c is not selected/ /***/ Display if Q7.5 d is not selected/ Which of your healthcare providers know that you currently smoke? Select all that apply. [Multiple answer MC] a. Neurologist * b. MS nurse ** c. General practitioner*** d. Other ____*** e. None
7.8	/ASK if Q3.2 a or b is selected: FORMER SMOKERS/ Have any of your healthcare providers congratulated you on quitting? [Single answer MC] A. No B. Yes, only one C. Yes, more than one D. I have not told any of my healthcare providers that I quit E. I am/was not seeing any healthcare providers F. Can't remember
7.9	/ASK if Q3.1 a or b is selected: CURRENT SMOKERS/ /ASK if Q3.2 a or b is selected: FORMER SMOKERS/ How satisfied are you with the support you have received regarding smoking from your healthcare providers? Please indicate why you were or were not satisfied. ⓘ Support can include information on smoking and/or quitting, including referrals to other services such as counselling and Quitline. [Single answer MC] a. Extremely dissatisfied _____ b. Somewhat dissatisfied _____ c. Neither satisfied nor dissatisfied _____ d. Somewhat satisfied _____ e. Extremely satisfied _____
7.10	/ASK if Q3.1 a or b is selected: CURRENT SMOKERS/ How would you feel if none of your healthcare providers ever discussed smoking with you? [Single answer MC]

	a. Relieved b. Nothing much c. Disappointed d. Other_____
7.11	/ASK if Q3.1 a or b is selected: CURRENT SMOKERS/ Which healthcare providers would you prefer to speak with regarding smoking and MS? Select all that apply. [Multiple answer MC] a. General practitioner b. Neurologist c. MS nurse d. Pharmacist e. Other ____ f. None
7.12	/ASK if Q3.1 a or b is selected: CURRENT SMOKERS/ /ASK if Q3.2 a or b is selected: FORMER SMOKERS/ Do you need additional information on smoking and quitting that is specific to MS? [Single answer MC] a. Yes, definitely b. Yes, somewhat c. No d. Not sure
7.13	/ASK if Q3.1 a or b is selected: CURRENT SMOKERS/ Which BEST describes how you (would) feel receiving information on the benefits of quitting on MS? [Single answer MC] a. This would motivate me to quit smoking b. This would motivate me to cut down on smoking c. It would make no difference d. This would cause guilt and stress, and prompt me to smoke more e. Other ____
8.0	PREFERENCE FOR SMOKING CESSATION SUPPORT
8.1	/ASK if Q3.1 a or b is selected: CURRENT SMOKERS/ Which of the following would you be interested in to help you quit smoking? Select all that apply. [Multiple answer MC] a. Nicotine replacement therapy products (e.g. nicotine patches, chewing gum) b. Stop-smoking medications such as varenicline (also known as Champix) or bupropion (also known as Zyban) c. Advice from my neurologist or MS nurse d. Advice from another doctor or healthcare provider e. Face-to-face advice from a smoking cessation expert, including counselling f. Telephone Quitline service g. Hospital-based service h. A special program for smokers who have MS

	i. Mobile-based programs such as phone apps j. Web-based program k. Internet sites for quitting advice and support l. Online support group m. Information brochures and booklets n. A workbook with tips and exercises to help me quit o. I don't want support for quitting
8.2	/ASK CURRENT AND FORMER SMOKERS/ How important is it that you receive quitting support from people with knowledge about MS, such as symptoms and medications? [Single answer MC] a. Extremely important b. Very important c. Somewhat important d. Not at all important e. I don't want quitting support
8.3	/ASK if Q3.1 a or b is selected: CURRENT SMOKERS/ /ASK if Q3.2 a or b is selected: FORMER SMOKERS/ How important is it that quit services address the following topics? [Matrix table: Extremely important, Very important, Somewhat important, Not important at all] a. Benefits of quitting on general health b. Benefits of quitting on MS c. Challenges that people with MS might face d. Withdrawal symptoms of quitting smoking e. Side effects of anti-smoking medication f. Interactions of anti-smoking medication with MS medication g. Effect of stress due to quitting on MS relapses h. Temporary worsening of symptoms due to quitting i. Weight gain j. Effect on mood k. Effect on relationships l. Other ____
8.4	/ASK if Q3.1 a or b is selected: CURRENT SMOKERS/ When do you think people with MS should be offered information about the benefits of quitting specific to MS? [Single answer MC] a. At time of MS diagnosis b. Within 1 month of diagnosis c. Within 6 months of diagnosis d. After 6 months of diagnosis e. Other ____ f. Never
8.5	/ASK if Q3.2 a or b is selected: FORMER SMOKERS/

	Please share your experience of what or who helped you quit and how quitting impacted on your health (optional). [Text entry] _____