

Willingness to receive a COVID-19 vaccine in people with multiple sclerosis – UK MS Register Survey

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Abstract

Background & Methods

We conducted an online COVID-19 survey as the vaccines became available, utilising the UK MS Register, to understand people with multiple sclerosis (pwMS) views on COVID-19 vaccination and the subsequent vaccine uptake rate.

Results & Conclusion

94.4% of 3191 pwMS surveyed indicated they would get a COVID-19 vaccine, while 5.6% would not. PwMS who have previously had an influenza vaccine, increasing age and the perception of having sufficient information about the vaccine were associated with increased likelihood of getting a vaccine. 51.7% of 3191 pwMS completed a follow-up survey indicating they received at least 1 dose of a COVID-19 vaccine. The proportion having had the vaccination based on their prior opinions was 53.2% in 'Yes' group and 27.0% in 'No' group, the latter reflecting a change based on their initial views. More information on COVID-19 vaccine safety in pwMS would be helpful for people to make informed decisions.

Keywords

Multiple sclerosis, COVID-19, vaccine / vaccination, UK MS Register

1 **1. Introduction**

2 Vaccination is the primary long-term strategy to manage the global impact of the SARS-CoV-
3 2, a novel coronavirus declared as a global pandemic in March 2020. However, there are
4 concerns whether various vaccinations in multiple sclerosis (MS) has been associated with
5 worsening of the disease (1, 2). Scientific consensus favours vaccinations in people with MS
6 (pwMS), with exceptions including pwMS on specific immunosuppressive disease-modifying
7 treatments (DMTs) and receiving ‘live’ vaccines around the time of treatment (3).

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9 It is essential to understand the acceptability of such an approach to maximise uptake among
10 the public but also in those who have specific risks such as pwMS. Acceptability of COVID-19
11 vaccines varies widely by country, ethnicity and age (4, 5) but crucially over time, as the
12 balance of disease risks versus the real or perceived risks of the vaccination evolves (5). Using
13 the UK MS Register (UKMSR), we launched a survey after the approval of the first COVID-19
14 vaccine in December 2020 (6), aiming to examine whether pwMS would get a COVID-19
15 vaccine and what factors may be playing a role in this decision process. We invited this cohort
16 of pwMS to answer a follow-up survey if they received a COVID-19 vaccine.

17 18 **2. Materials and Methods**

19 PwMS on the UKMSR (Ethics:16/SW/0194, explicit consent gained) were invited by email to
20 complete a COVID-19 vaccine online questionnaire between 7 December 2020 and 19 January
21 2021. Questionnaires were linked to age, gender, highest educational attainment (‘University’
22 or not), MS disease type (‘progressive’ – primary progressive and secondary progressive MS,
23 ‘non-progressive’ – relapsing remitting MS, benign and others), whether currently on a

24 disease-modifying treatment (DMT), anxiety was assessed using the Hospital Anxiety and
25 Depression Scale (HADS) score (≥ 8) and disability was measured using the MS Impact Scale
26 (MSIS-29) normalised physical subscore. Further factors considered include previous
27 childhood, adolescent, travel and influenza vaccinations history and whether pwMS felt they
28 have enough information on the COVID-19 vaccines. PwMS are stratified as an at-risk priority
29 group [group 6 or above] by the Joint Committee of Vaccination and Immunisation (JCVI) in
30 the UK (7) and should have been offered a COVID-19 vaccine by March 2021. Therefore,
31 pwMS were invited to complete a follow-up questionnaire between 19 December 2020 and
32 20 May 2021, confirming if they have received at least 1 dose of a COVID-19 vaccine.

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34 Statistical analysis was performed using the R statistical programming language (version
35 3.5.1). Univariate (t-test, Chi-squared and Kruskal-Wallis test) and logistic regression analyses
36 were used to compare whether the above factors were associated with a difference in
37 likelihood of getting a COVID-19 vaccine. Free text responses were categorised independently
38 by two assessors (YH and RN).

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40 **3. Results**

41 3191 out of 5189 pwMS contacted completed the questionnaire (61.5% response rate). 94.4%
42 (3013/3191) of pwMS indicated they would get the vaccine (69.4% 'definitely', 16.1%
43 'probably', 9.0% 'possibly') and 5.6% (178/3191) would not (3.3% 'probably not' and 2.3%
44 'definitely not') (Figure 1A).

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46 Univariate analysis (Table 1) showed factors including increasing age, male gender, pwMS
47 who had adolescent vaccines, the influenza vaccine and pwMS who feel they have enough

48 information about COVID-19 vaccines were associated with higher proportion of 'Yes'
49 responses to a COVID-19 vaccine. Childhood and travel vaccinations were excluded due to the
50 limited numbers declared taken. Logistic regression (Table 1) found increasing age was
51 associated with increased likelihood of a 'Yes' response (Figure 1B). In contrast to the
52 univariate analysis, pwMS with a university level education were 1.89 times, those on DMTs
53 were 1.73 times and pwMS who had an influenza vaccine previously were 7.08 times more
54 likely to have the COVID-19 vaccine. PwMS who felt they have sufficient information were
55 2.03 times more likely to get a COVID-19 vaccine.

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57 The top two reasons for not getting a COVID vaccine (n=178) are safety concerns and not
58 enough information (Figure 1C). Free text analysis (165/178) found 47.3% (78/165) required
59 further information and were concerned about the unknown long term side effects, and the
60 speed COVID-19 vaccines have been developed and approved.

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62 57.6% (1839/3191) of pwMS felt they do not have enough information about the COVID-19
63 vaccines. PwMS who received information (Figure 1D) from the news (88.1% [2812/3191]),
64 charitable organisations (36.1% [1153/3191]) and family (18.3% [585/3191]) were **4.79**
65 **(3.35,6.82,p=0), 2.31 (1.61,3.38, p<1x10⁻⁵) and 2.03 (1.21,3.55, p<0.0096) times more likely**
66 **to get a COVID-19 vaccine.** Comparatively, pwMS who received information from social
67 media (17.5% [557/3191]) and scientific articles (32.3% [1030/3191]) were less likely to get
68 a COVID-19 vaccine (0.58 (0.4,0.87, p<0.0069) and 0.61 (0.44,0.86, p<0.0046) respectively) .
69 Only 7.2% (229/3191) have received advice about vaccination from their MS team and 2.8%
70 (89/3191) from their GP. 72.4% (2311/3191) would like more advice on the risk of causing a
71 relapse and whether the vaccine will be effective with DMTs (Figure 1E).

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Logistic regression analysis showed younger age group (0.97 [0.96,0.98], $p<0.0001$), female gender (0.77 [0.61,0.97], $p=0.0027$), no university-level degree (0.65 [0.52,0.82], $p=0.0003$), not progressive MS (0.58 [0.45, 0.74], $p<0.0001$), more disabled (1.40 [1.08, 1.82], $p=0.0012$) and never having had an influenza vaccine (0.58 [0.37, 0.90], $p=0.017$) were associated with increased perception of insufficient information.

The follow-up survey found 51.7% (1650/3191) of pwMS who had completed the initial survey had received at least one dose of a COVID-19 vaccine by 20th May 2021, a median of 67 days after the initial survey. The majority (55.5%) of pwMS received the Oxford / AstraZeneca vaccine (Figure 2A) and 50.0% received the vaccine at the vaccination centre. Of those who said they would get a COVID-19 vaccine, 53.2% (1602/3013) had received it and in those who initially indicated they would not get a vaccine, 27.0% (48/178) had received it (Figure 2B).

4. Discussion

This online survey performed in the early phases of vaccine availability showed 94.4% of pwMS would accept a COVID-19 vaccine. This is a higher rate compared to online surveys conducted around similar time period, the UK general public (67%) (8), patients with autoimmune diseases from Netherland (61%) (9), pwMS from Portugal (80.9%)(10) and pwMS from US in April 2020 (66%) (11). In common with previous surveys, increasing age (8-10, 12), higher level of education (8, 11, 12) and in those who have previously had an influenza vaccine (13) had an increased likelihood of getting a COVID-19 vaccine. Interestingly, while there are now concerns around vaccination efficacy in those on DMTs (14), pwMS on DMTs were 1.7 times more likely to take a COVID-19 vaccine.

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A key message was that if pwMS had sufficient information, they were twice as likely to get the vaccine. The perception of receiving sufficient information is a significant factor in the decision process for 58% of those surveyed. Most pwMS receive information about COVID-19 vaccines from sources associated with a higher level of COVID-19 vaccine acceptance [The News, charitable organisations] compared to social media (12). However, pwMS who received information from scientific articles were also less likely to receive a COVID-19 vaccine, which may reflected the general lack of scientific evidence for vaccine safety in pwMS in scientific publications during the early phase of vaccine availability. Overall, vaccine hesitancy is predominately due to a desire to gain more information to make informed decisions. We characterised the groups who need to be targeted with more information, it appears to be those at lower risk from COVID-19 e.g. younger, non-progressive MS and female gender; those less likely to have a university-level degree; those who are more disabled and those who have never had an influenza vaccine.

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The follow-up survey had a response rate of 51.9% and found that 53.2% of pwMS who initially said 'Yes' to a COVID-19 vaccine received at least one dose by 20th May 2021. This could be an underestimate if pwMS did not answer the follow-up survey or were not offered a COVID vaccine due to local availability. Interestingly, 27.0% of pwMS who initially said 'No', went on to have a COVID-19 vaccine. The difference between the initial surveyed opinion in the early phases of vaccine availability and the final decision to receive a COVID-19 vaccine reflects the complex, multi-factorial and continuously evolving perception of disease risks versus the risks and benefits of vaccine over time (5). However, with further information initially hesitant pwMS decided to proceed with vaccination. A limitation of this study is the

120 response rates of 61.5% in the initial survey and 51.9% in the follow-up survey, which may
121 reflect responses from people who are more health conscious or stronger opinions on health-
122 related issues.

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124 **5. Conclusions**

125 The majority of pwMS are willing to have a COVID-19 vaccine when made available. The
126 primary reasons for not having a COVID-19 vaccine include safety concerns and insufficient
127 information. Specifically, pwMS would like more information on the impact of a COVID-19
128 vaccine on MS disease activity and potential interactions with MS treatments. The final
129 decision to receive a COVID-19 vaccine changes over time with evolving perceived risks versus
130 benefit.

131

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134

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139 **Declaration of Conflicting Interests**

140 The Authors declare that there is no conflict of interest.

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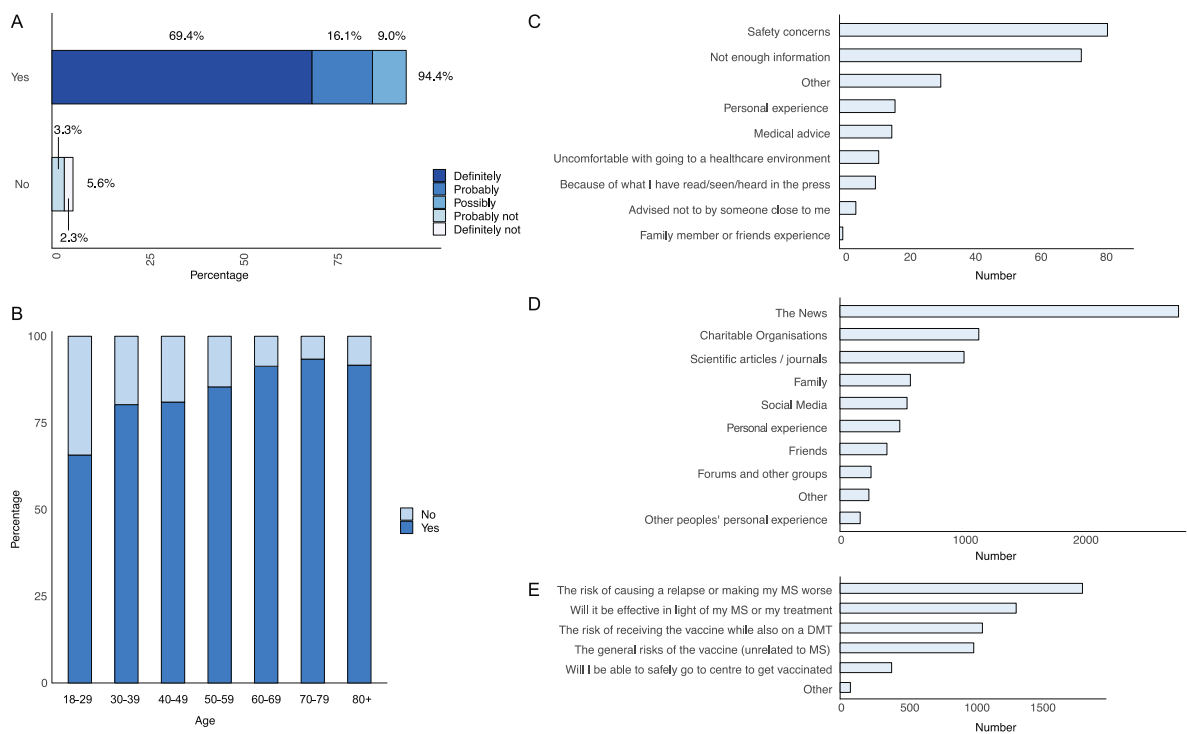


Figure 1. A) Bar graph of the responses of pwMS to getting a COVID-19 vaccine (n = 3191), expressed as a percentage of the total number. This was grouped into ‘Yes’ responses, including definitely, probably and possibly to a COVID-19 vaccine; and ‘No’ responses, including probably not and definitely not to a COVID-19 vaccine. B) Bar graph showing the

proportion of 'Yes' and 'No' responses to a COVID-19 vaccine by age group, n = 3189. C-E) Bar graphs showing the frequency of the multiple-choice answers from the survey. C) Reasons why pwMS would not take a COVID-19 vaccine. Total number of participants = 178, total number of responses = 249. D) The sources pwMS receive information about the COVID-19 vaccines. Total number of participants = 3191, total number of responses = 7960. E) Areas where pwMS would like more information about the COVID-19 vaccines. Total number of participants = 3191, total number of responses = 5729.

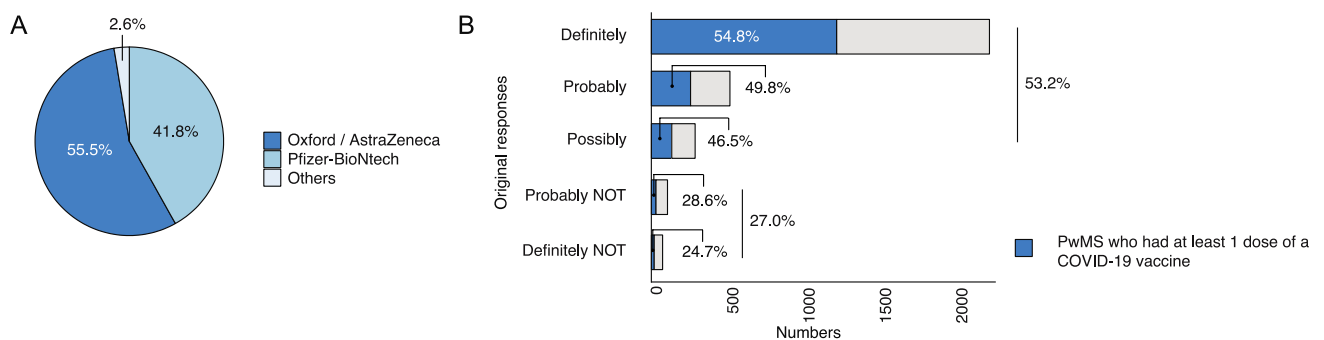


Figure 2. A) A pie chart of which COVID-19 vaccine pwMS received. B) A bar plot of the proportion of pwMS who received at least one dose of a COVID-19 vaccine, based on their original response to whether they will get a COVID-19 vaccine if offered. N=1650.

Variable	Univariate analysis		p	Logistic regression analyses OR 95% CI [lower, upper], p		n
	No	Yes				
Age: years	49.06 (11.33)	53.66 (11.43)	<0.001	1.05 [1.02, 1.07], <0.001	3189	
Gender: Male	34 (19.21%)	811 (26.94%)	0.029	1.17 [0.68, 2.12], 0.579	3187	
Education: University	32 (23.36%)	690 (31.15%)	0.068	1.89 [1.07, 3.55], 0.037	2352	
On DMT: Yes	54 (30.34%)	1093 (36.28%)	0.127	1.73 [1.01, 3.02], 0.047	3191	
Progressive: Yes	58 (32.58%)	1068 (35.46%)	0.485	0.86 [0.46, 1.6], 0.638	3190	
Anxiety: Yes	43 (43.00%)	691 (35.84%)	0.178	0.81 [0.48, 1.37], 0.441	2028	
Motor Disability - normalised MSIS-29 score: upper quartile >59	29 (27.62%)	497 (25.47%)	0.707	1.00 [0.98, 1.01], 0.648	2056	
Adolescent Vaccines: No	10 (5.62%)	51 (1.69%)	0.003	0.74 [0.18, 5.29], 0.714	3191	
Unsure	10 (5.62%)	145 (4.81%)		1.68 [0.55, 7.48], 0.421		
Have you ever had an influenza vaccine: Yes	1.18 (66.29%)	2853 (94.69%)	<0.001	7.08 [4.14, 11.92], <0.001	3191	
Do you have enough information: Yes	46 (25.84%)	1306 (43.35%)	<0.001	2.03 [1.19, 3.58], 0.011	3191	

Table 1. Univariate and logistical regression analysis, comparing whether the variables are associated with a difference in the likelihood of getting a COVID-19 vaccine. For univariate analysis, Age is expressed as mean and standard deviation for each response. Reference groups for the subsequent variables are: Gender – female; Education – no university level education; On DMT - no; Progressive - No; Anxiety - No; Motor disability – normalised MSIS-29 physical score <59; Adolescent Vaccine: Yes; Have you ever had an influenza vaccine: NO; Do you have enough information: NO. The percentage is the variable that answered ‘No’ or ‘Yes’ expressed as a proportion of the total numbers that answered ‘No’ or ‘Yes’ in each category.