A large, stylized graphic element consisting of several overlapping, rounded triangular shapes in various shades of orange and yellow, creating a sense of depth and movement. The central text is placed within one of these shapes.

**Covid-19 Vaccines and  
potential risk of side  
effects for people with MS**

COVID-19 Vaccines – Evidence to  
support more informed decision  
making for people with MS

March 2021

Let's stop MS **together**

## Section 1: Introduction

We've developed this briefing to make sure people with multiple sclerosis (MS) and their healthcare professionals have the most up-to-date information about the potential risk of side effects from available COVID-19 vaccines. Our findings provide a snapshot of the types of vaccine administered and, more importantly, the symptoms people with MS have reported experiencing post vaccination. We hope that this evidence will help people with MS make more informed decisions about being vaccinated.

### About the survey

The findings presented within this briefing are taken from the UK MS Register online COVID-19 Vaccination Questionnaire and include all the 2,348 complete responses for period 19 December 2020 - 17 March 2021.

The questionnaire is open to any person within the UK, aged 18+years who has received an MS diagnosis. If you are eligible and would like to take part or would like more information on the MS Register please visit <https://ukmsregister.org/>.

### The MS Register

The UK MS Register was launched in 2011 by the team at Population Data Science in Swansea University Medical School and is funded by the MS Society. The fundamental concept is to capture more real-world data about living with MS in the United Kingdom.

### About the data

- a) Limited survey responses (2348 people responded) mean our findings cannot be generalised to all people with MS.
- b) The data is reported directly from people living with MS and is therefore subjective in nature – the severity of side effects could be viewed differently depending on the individual.
- c) The data is not peer reviewed (other experts in the field have not examined the data).
- d) Our findings corroborate those derived from the Yellow Card Scheme run by the Medicines and Healthcare Products Regulatory Agency (MHRA) – (see section 3 for more details).
- e) The types of vaccines included in the data are: 1,260 Oxford AstraZeneca vaccine, 1,020 the Pfizer-BioNTech and 15 Moderna.
- f) Any reactions or side effects reported cannot be directly linked to the vaccine.
- g) The data only includes first doses.

## About the survey respondents

The total number of people to complete a questionnaire was 2348.

The majority of respondents (76%) were female, over half of whom (60%) reported having relapsing remitting MS (RRMS). Male respondents accounted for 22% of the

sample, 54% of males reported having progressive MS. Please note that in this survey “progressive MS” means both primary and secondary progressive MS. The types of MS experienced by respondents corresponds with proportions in the overall MS population (43% RRMS, 15% progressive MS) <sup>i</sup>.

The age ranges of respondents are skewed to older age categories, the average age for females is 58 years and 61 years for males (see Figure 1). The gender of respondents corresponds with the overall MS population 2020 (Females= 73% Males=27%).

### MS and the vaccine



2,348 people with MS told us about their experience of having a COVID-19 vaccine.

**Figure 1. Respondents (MS type, gender and age)**

Gender	Mean Age (years)	MS Type	N
<b>Female (78%)</b>	58	Progressive	598
		Relapsing	1087
		Other	135
<b>Males (22%)</b>	61	Progressive	283
		Relapsing	205
		Other	29

Note: 1 person omitted due to the potential to identify them through responses

## Section 2: The findings

### 1. Where did you get your vaccine?

The majority of survey respondents (84%) received their vaccine in England. 8% of vaccinations were administered in Scotland, 6% Wales and 2% Northern Ireland (2.97% were unknown). The percentage of vaccines administered across nations is comparable to population density (See Section 3 for latest UK vaccination figures).

#### Where did you get the vaccine?

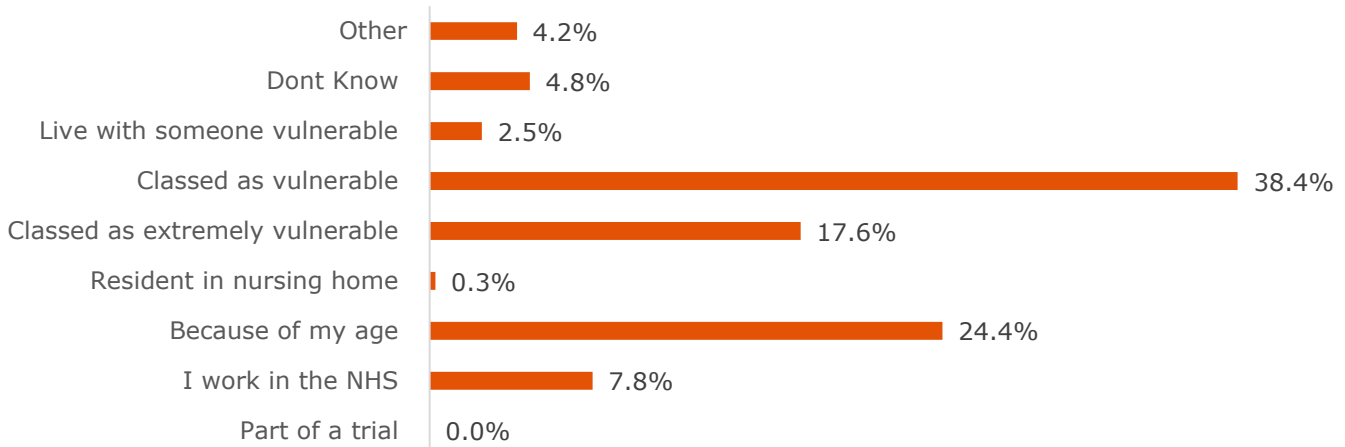
- England - 84%
- Scotland - 8%
- Wales - 6%
- Northern Ireland - 2%



### 2. Why are people with MS having the vaccine?

As expected, over half of respondents (56%) cited being clinically vulnerable as a reason for getting the vaccine. Being in an older age category was also revealed as a major reason (24%) for having the vaccine. Our findings reflect the vaccine roll out strategy, which prioritises people based on older age and other risk factors – see Figure 2 (See section 3 for details on the top six priority groups).

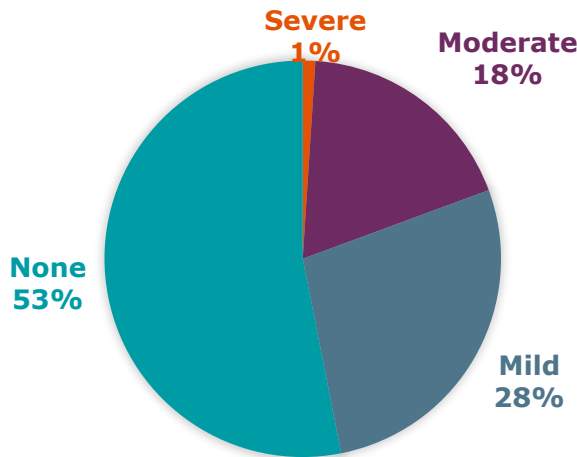
**Figure 2. Why did you have the vaccine?**



### 3. Did you have a reaction to the vaccine?

Over half (53%) of those who received the vaccine reported having no reaction at all and 47% experienced some degree of reaction. Out of those who had a reaction, only 24 described symptoms as severe. Our data tells us that if a reaction is experienced, it is much more likely to be mild to moderate – see Figure 3.

**Figure 3. Reaction and severity to the vaccine**

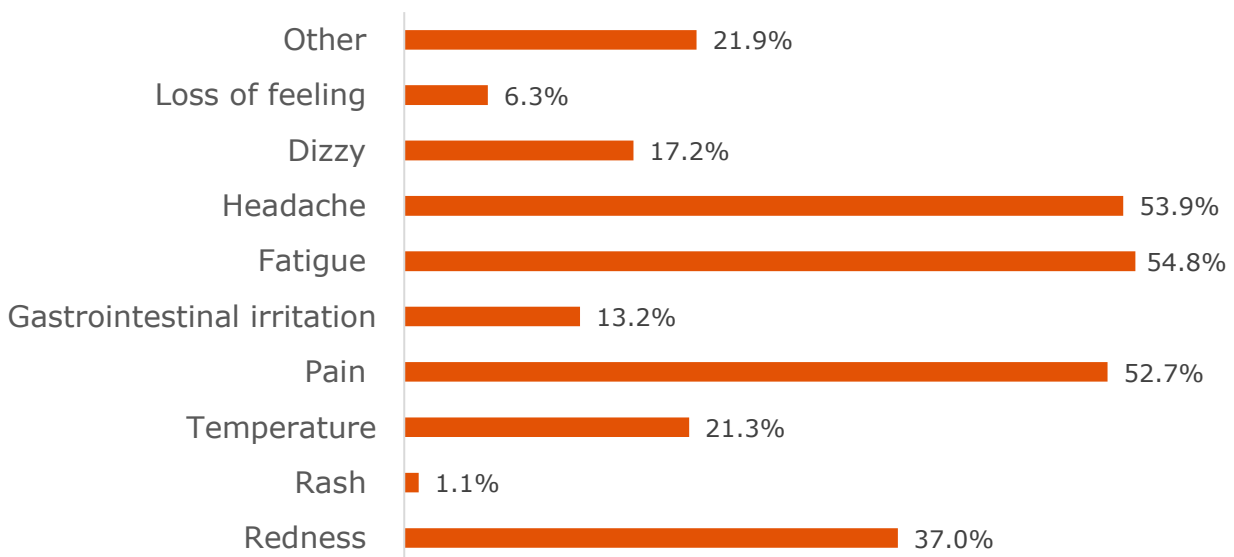


Note: reactions to vaccines are self-reported and so subjective

### 4. What side effects did you experience?

If reactions did occur, the most common side effects people with MS reported were: fatigue (55%), headache (54%), pain (53%) and redness (37%).

**Figure 4. Types of side effects experienced**



Note: this question is select all that apply.

If you receive the vaccine, you can report any suspected side effects to the MHRA at [coronavirus-yellowcard.mhra.gov.uk/](https://coronavirus-yellowcard.mhra.gov.uk/)

## Conclusion

1. People with MS considered “clinically extremely vulnerable”, or within older age brackets, are most likely to have been vaccinated.
2. Most people have had either the Oxford AstraZeneca or Pfizer-BioNTech vaccine. The split between the two is fairly even.
3. More investigation is required into whether people have different responses to different vaccines.
4. Less than half of people who had the vaccine reported experiencing a reaction. If they did, their reactions were likely be mild to moderate with only 1% reporting a severe reaction (in this survey, severe does not necessarily mean a severe allergic reaction).
5. If a reaction does occur, the most common side effects reported were fatigue, headache, redness and pain. Note – we cannot evidence a direct link between the vaccination and any symptoms reported.
6. Early data from the MHRA Yellow Card Scheme (see section 3), has demonstrated similar mild/ moderate symptoms within the general population.
7. Further investigation is required into the MS population and side effects.

## Section 3: Notes on interpretation of data

<sup>[1]</sup> The Yellow Card Scheme is run by the Medicines and Healthcare Products Regulatory Agency (MHRA) which is an executive agency of the Department of Health and Social Care. The MHRA is responsible for ensuring that medicines and medical devices work and are acceptably safe.

The MHRA, publishes weekly reports summarising Yellow card reporting based on its monitoring of the vaccine roll out. To date, they have found that the vast majority of reported side effects are mild and short-lasting, and a normal response to vaccines.

‘For both vaccines, the overwhelming majority of reports relate to injection-site reactions (sore arm for example) and generalised symptoms such as ‘flu-like’ illness, headache, chills, fatigue (tiredness), nausea (feeling sick), fever, dizziness, weakness, aching muscles, and rapid heartbeat. Generally, these happen shortly after the vaccination and are not associated with more serious or lasting illness.

‘These types of reactions reflect the normal immune response triggered by the body to the vaccines. They are typically seen with most types of vaccine and tend to resolve within a day or two.

‘The nature of reported suspected side effects is broadly similar across age groups, although, as was seen in clinical trials and as is usually seen with other vaccines, they may be reported more frequently in younger adults’:  
<https://www.gov.uk/government/publications/coronavirus-covid-19-vaccine-adverse-reactions/coronavirus-vaccine-summary-of-yellow-card-reporting>

Yellow Cards are available from pharmacies and GP surgeries or from the Yellow line by calling Freephone 0800 731 6789 during business hours or email <https://yellowcard.mhra.gov.uk/the-yellow-card-scheme/>

[ii] The demographical data is representative of males and females with MS in the UK: <https://www.mssociety.org.uk/what-we-do/our-work/our-evidence/ms-in-the-uk>

Relapsing remitting MS (RRMS) is the most common form of MS, and around 85% of people with MS are initially diagnosed with this type of MS – some of whom will later go on to develop secondary progressive MS (SPMS). About 10-15% of people with MS are diagnosed primary progressive MS (PPMS). Estimates of the proportion of people with RRMS at a given time range between 31% - 55%. The MS Society has sometimes used the mid-point of these studies, 43%, to provide a rough estimate the proportion of people with RRMS currently.

[iii] In the survey, the proportions of people having their vaccine in each nation match the density of population. It’s not likely to be linked to the rollout of the vaccine: <https://coronavirus.data.gov.uk/details/vaccinations>

[iv] The people who’ve responded to the survey so far match the UK vaccine priority groups: <https://www.gov.uk/government/publications/covid-19-vaccination-care-home-and-healthcare-settings-posters/covid-19-vaccination-first-phase-priority-groups>.)

[v] Adverse reactions to vaccines have been found to be mild or moderate in some members of general population. Further investigation is required into the MS population and side effects.  
<https://www.gov.uk/government/publications/coronavirus-covid-19-vaccine-adverse-reactions/coronavirus-vaccine-summary-of-yellow-card-reporting>

## **We're the MS Society.**

Our community is here for you through the highs, lows and everything in between.

We understand what life's like with MS.

Together, we are strong enough to stop MS.

[mssociety.org.uk](http://mssociety.org.uk)



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 **Let's stop MS together**