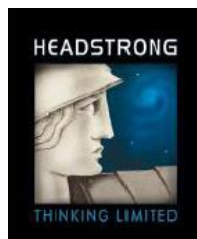


Exploring the potential to use communication to change  
behaviour among people with MS who are smokers

Final report

Headstrong Thinking Limited

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## 1 Introduction to the research

### 1.1 Background

The MS Society is seeking to change behaviour across three areas (Disease Modifying Therapies, physical activity and smoking) to empower people with MS to make informed decisions in relation to their physical and mental wellbeing.

A campaign on smoking will begin in September 2018, encouraging people with MS to take part in the challenge month of Stoptober, working alongside Public Health England.

There is strong evidence that smoking is a risk factor in developing MS and increasing evidence suggesting it is a factor in MS getting worse. The Society's evidence review suggests smoking should be avoided by people with MS and close relatives of people with MS. Not all studies are consistent, but a number show that smoking can make MS more active; worsen and speed up the accumulation of disability; raise the risk of getting progressive MS; and speed up the transition from relapsing remitting to secondary progressive MS. There are of course also broader health benefits to quitting.

Behaviour change work on smoking will initially 'target' people with MS, rather than their family members who smoke or people at risk of developing MS.

### 1.2 Research Objectives

- To identify the barriers to stopping smoking for people with MS
- To recommend messages relating smoking to MS, which might persuade someone to quit (i.e. change their behaviour)

The discussion guide for the research is appended but the key areas for questioning in relation to barriers and messaging were as follows:

- Reasons for starting smoking and timeline in relation to MS diagnosis.
- Role of smoking in the smoker's life. When they smoke, who they smoke with and how they feel about being a smoker
- Status of MS symptoms and feelings about how well MS is being managed
- Experience of quitting or quit attempts – key to success (quitters in the sample); reasons for lack of success and/or lack of motivation to attempt to quit
- Smoking and MS – awareness, if any, of a link between smoking and a (negative) impact on MS. Perceived role of smoking, if any, in the smoker's response to or management of their MS.
- Response to messaging about the potential harmful effect of smoking on MS (progression) and likelihood to prompt behaviour change. Most effective messaging approach(es) and most powerful support to underpin messaging.

### 1.3 Research methodology

The methodology was chosen to meet the objectives as follows.

The research was balanced in terms of focus with an early stage of information gathering about barriers and awareness of a link between smoking and (progression of) MS followed by two rounds of message testing. The first of these looked at four propositions crafted after the initial information gathering stage. The second explored propositions which had been revised after feedback from smokers and also introduced an additional proposition. All propositions (original and revised) are appended. As part of stage one (information gathering), six smokers were to be invited to complete a five-day smoking diary followed by a telephone interview. We were interested in drawing smokers' attention to their smoking habit so that they could discuss it in depth as part of their interview covering all aspects of smoking. In the event we found it difficult to get smokers who were prepared to do this task and recruited five – three of whom returned their diaries and two of whom did not (despite reminders). Further comment on this aspect of the study's recruitment and other recruitment challenges are explored in appendix 1.

### 1.4 Recruitment of participants

The MS Society created an initial screening questionnaire which was publicised using Twitter and Facebook. This resulted in an initial response from 102 eligible participants with MS (from a larger pool): – 42 smokers; 42 quitters and 18 vapers (in practice also quitters). Individuals were asked about their date of diagnosis with MS, their status as a smoker, ex-smoker and/or vaper and requested to provide a phone number and email address. They opted in at that point to further contact from two named third parties: Headstrong Thinking Ltd and their subcontracted market research participant recruitment company, Talking Matters Ltd. This pool was subsequently topped up for the second round of proposition testing, as Talking Matters ran out of smokers willing and eligible to take part. Our total sample of twenty seven participants was drawn from these two pools.

Talking Matters were responsible for contacting potential participants, usually by phone and asking them to commit to an interview. Headstrong Thinking then conducted interviews either online or more usually as telephone interviews. There were some issues about recruitment relating to the need to complete a consent form for the MS Society before the interviews could take place. Essentially the need to complete the form reduced substantially the number eligible to take part, as many did not complete and return it. As an alternative, we received permission from the MS Society to administer the form at the beginning of each interview.

### 1.5 Research sample

- All the participants were people with MS (mainly individuals with RRMS with three participants having progressive MS – two secondary progressive and one primary progressive).

- We recruited a mix of current smokers and ex-smokers (quitters) in order to assess the barriers to quitting; motivations to quit and influence or otherwise of an MS diagnosis or (worsening) symptoms of MS on motivation or attempt to quit.
- We recruited people with a range of length of time since diagnosis to assess whether awareness of smoking and its deleterious effect on MS has grown in recent years.
- We obtained information about the participant's occupation or former occupation and current relevant benefit status to establish their socioeconomic grade.
- A mix of male and female participants and individuals of different ages were recruited.
- We did not quota on how long individuals had been smokers (either before they quit or to date). It is interesting that the sample obtained was skewed towards those who have smoked for many years, starting in the overwhelming majority of cases when they were aged 14-19. We understand that this is consistent with national data – two thirds of all current smokers started before age 18<sup>1</sup>.
- Similarly, we did not quota on how many cigarettes they smoke(d) daily (but recruited only those who smoked at least 5 cigarettes a day). A good spread was achieved within the range 5 - 40 cigarettes a day

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<sup>1</sup> Action on Smoking and Health (2018): Statistics on Smoking

The following table shows the demographic profile and other details of the sample, at each stage of the research. Details of smoking habits are found in the detailed findings section of the report.

Table 1: Demographic profiles	Quitters	Diary participants – smokers	Phase one propositions smokers	Phase two propositions smokers	TOTAL
(NOS)	(8)	(5)	(7)	(7)	(27)
Gender:					
Male	4	1	1	1	7
Female	4	4	6	6	20
Age band:					
25-34	1	1	1	1	4
35-44	0	0	3	4	7
45-54	4	2	2	2	10
55-64	1	2	0	0	3
65+	2	0	1	0	3
SEG: AB	4	1	2	3	10
C1	0	0	4	2	6
C2	0	0	0	0	0
DE	2	1	1	1	4
PIP**	0	1	1	4	6
ESA**	1	0	0	2	3
DLA**	0	2	0	1	3
Company **scheme invalided out	1	0	0	0	1

- \*\* additional classification. Each individual was first classified based on their current or former occupation under the ABC1C2DE classification of socio economic grade (SEG) which includes those on a state pension who are classified as "E".
- Those now living on state benefits alone (other than a state retirement pension) were not classified within SEG "E" (contrary to the classification description below) but classified instead by their former occupation. However, we have also recorded, as additional columns, the benefit recipient count for (ESA/PIP/DLA)

. **Social Grade classifications:**

- **A** Higher managerial, administrative or professional
- **B** Intermediate managerial, administrative or professional
- **C1** Supervisory, clerical and junior managerial administrative or professional
- **C2** Skilled manual workers
- **D** semi and unskilled manual workers
- **E** state pensioners, casual or lowest grade workers, unemployed with state benefits only

Social grade is a classification system derived from the British National Readership Survey (NRS). It is based on occupation and it enables a household and all its members to be classified according to the occupation of the Chief Income Earner (CIE). In addition, if the respondent is not the CIE and is working, then the social grade of that individual is also recorded. Here we have recorded the social grade of the individual participant

## 1.6 Behaviour change and COM-B

Professor Susan Michie and colleagues at University College London have developed a model for behaviour change, widely-used in public health marketing, known as COM-B<sup>2</sup>.

COM-B is an acronym: **C**apability, **O**pportunity, **M**otivation – **B**ehaviour:

- **Capability** – the ability to make the change, which includes psychological or physical ability to enact the behaviour
- **Opportunity** – the chance or means to change, which includes the physical and social environment that enables the behaviour
- **Motivation** – the desire to change, which includes reflective and automatic mechanisms that activate or inhibit behaviour

The model argues that, for an individual to change their behaviour, all three factors must be in place. Crucially, the model also argues that, while increasing capability and opportunity can both increase motivation (if I feel I can do something or am given an opportunity to try it, I may feel more inclined to do it), boosting motivation does not impact on capability (I may really want to do

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<sup>2</sup> Michie, S, et al (2011) The behaviour change wheel: A new method for characterising and designing behaviour change interventions. *Intervention Science*. 2011; 6: 42.

something, but if I can't or don't have a chance to, I won't). COM-B has been widely applied in public health marketing.

Irrespective of whether an individual has MS, capability, opportunity and motivation are all relevant in the context of smoking (and smoking cessation) behaviour. The following examples illustrate the model in relation to smokers as a general population<sup>3</sup>:

### Capability

- Smoking is an addiction; people may wish to quit, but feel they cannot
- Cigarettes can be deeply engrained into people's lives. This means quitting is not a single behaviour change: it is an ongoing, daily, multiple behaviour change in which many cigarette occasions each have to be relinquished
- Quitting capability can be encouraged or sabotaged by others (for example, friends and loved ones, who either want to help the smoker give up or, being smokers themselves, want to keep the smoker in their "club")

### Opportunity

- While most smokers say they want to quit, it can be hard to find the perfect opportunity to do so.
- While smoking is a minority pursuit, the visibility of smoking can make it seem more common (and "normal") than it is. The more smokers there are within an individual's social group (family, friends, work colleagues), the more likely that individual is to smoke.

### Motivation

- Smoking can be attractive as both a solitary pursuit (a "moment that is just for me") and a social pursuit; among smokers whose friends smoke, quitting can feel like ostracism.
- Smokers may have shorter time horizons, i.e. value an immediate benefit (the "pleasure" of a cigarette) disproportionately over longer term benefits (such as better health in later life)

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<sup>3</sup> Public Health England (2018) Tobacco Control Marketing Strategy



## 2 Executive summary and recommendations

The MS Society planned a campaign on smoking to begin in September 2018, encouraging people with MS who smoke, to take part in the challenge month of Stoptober working alongside Public Health England. This campaign formed part of a wider initiative seeking to change behaviour across three areas (Disease Modifying Therapies, physical activity and smoking) to empower people with MS to make informed decisions in relation to their physical and mental wellbeing

This research study was conducted in the early summer of 2018 by Headstrong Thinking Ltd, an agency specialising in research and behaviour change. The objectives of the study were to explore the attitudes; knowledge and behaviour of two groups - smokers and quitters, with MS. The MS Society needed to understand what this sample knew about the risks of smoking with MS and to explore their responses to a series of messaging options (propositions). The COM-B<sup>4</sup> model of behaviour change was used to assess the findings from participants in the research and to produce a recommendation about the optimum behaviour change approach to messaging to support the autumn campaign.

In total eight quitters and nineteen smokers with MS took part in the research. All were initially recruited by the MS Society and "opted in" for third party contact. The majority were then interviewed by Headstrong Thinking, by telephone with a further two individuals responding on line. The "quitter" sample provided insight into whether MS was seen as a deciding factor in giving up smoking and what knowledge participants had about the risks of smoking with MS. The smoker sample provided further background insight into smoking and MS (five participants). Seven further smokers assessed initial propositions and a further seven reviewed revised propositions.

The overwhelming majority of participants in the study did not know anything about the risks of smoking with MS. The exceptions were two participant smokers whose neurologist had advised against continuing to smoke with MS *and tied that advice to MS specific risks* – namely that MS can accelerate the progress of the disease. One further ex-smoker was advised not to start smoking again if he wished to be prescribed a DMT, (Tysabri), because of the possibility of smoking compromising the effectiveness of the drug. No one else mentioned (spontaneously or when prompted) any health risks of smoking with MS, other than the general health risks that any smoker might face. This group claimed that their neurologist had not mentioned specific risks about MS and smoking. A small number reported that healthcare professionals (HCPs) suggested they delay giving up until the shock of their diagnosis had receded. No one amongst the eight participants who had quit, had quit because of their MS except for one individual who was convinced that smoking had directly exacerbated symptoms of his MS (which at the time was just

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<sup>4 4</sup> Michie, S, et al (2011) The behaviour change wheel: A new method for characterising and designing behaviour change interventions. *Intervention Science*. 2011; 6: 42.

being diagnosed). Others had quit for other non MS related health reasons or because, like any smoker, they had finally resolved to do so.

Smokers and quitters in this sample did not see themselves as smokers in a special category "smokers with MS". They displayed many of the same attitudes and beliefs (and barriers to quitting) that any smoker would articulate. Barriers included fear of quitting and anticipated losses - elevated by previous failed attempts to quit, which all reported. Some stated that living with a smoker or having close family who smoke, made quitting even harder. Nearly all expressed a dislike of smoking and a desire to quit but all recognised their addiction for what it was. Many felt a sense of shame about smoking and felt they were fast becoming a pariah in society.

There was some evidence in responses, that having MS does negatively impact upon smoking behaviour – both the decision to continue smoking and the number of cigarettes the individual might smoke. These influences were not generally top of mind for the individual smoker, who usually had never given a thought to a connection – positive or negative – between their MS and smoking.

MS is a stressful disease to manage. Some smokers in the study realised in discussion that smoking helped them manage stress. They felt that giving up would be bad for their MS as it would take away an ally in stress management. Furthermore, like all smokers, they feared giving up and felt that doing so would add extra stress which in turn might impact their MS. Specific to MS, a small number of participants also realised during the interview that continuing to smoke was sometimes a reaction to getting a diagnosis (and denying and resisting having MS). Smoking was reported as a rebellious act in such cases. There was a related finding that some people felt that MS had robbed them of a great deal of control of their lives and their bodies and that continuing to smoke was one small thing they could keep for themselves as a person (not related to their MS label). Others reported that having to give up work because of their MS had left them with more time, more isolation, lack of stimulation, boredom and depression. In these circumstances some reported that their smoking levels had begun to creep up as smoking started to fill gaps in their lives, perhaps making it harder to resist or control.

A number of participants were very defensive. This was demonstrated in a resistance to take on board any messages about why they should quit (relating to general smoking cessation advice as well as our tailored messaging about MS and smoking). This is symptomatic of their addiction to cigarettes and is found in other research around smoking cessation. The insidious relationship between smoking (more) and their MS, which we have outlined here, sometimes served in our interview, to further entrench that defensiveness.

There were other participants who did show some shift in their resolve to quit smoking after exploring the propositions we put to them. This group was not distinctive in terms of their smoking behaviour or length of time/severity of their MS. They were no more likely to be heavier smokers, or longer-term smokers than the sample as a whole. Nearly everyone in the sample had been smokers since their teens. What influenced them was a desire to quit and hearing new facts

about how continuing to smoke might impact on their MS and its progression. The loss framing and gain framing propositions we put to smokers were most likely to prompt a shift in motivation. Although gain framing generally communicates the gains smokers will see if they give up, the greatest impact of this proposition was in fact grounded in a fear it raised (more like a loss framing approach). In both approaches it was fear of disability and disease progression that proved the most arresting facts. The supporting statement that “smokers who quit smoking could delay the onset of secondary progressive MS by as much as eight years” triggered fears about disease progression – either the worsening of disability or progression to secondary MS. The recommended messaging combined these facts into a loss framing approach, based on the fears people with MS expressed about disease progression and disability. Physical disability was the frame most likely to promote fear in relation to disease progression.

Talking about damage being done without the smoker realizing it (“hidden harm”) was also motivating. It is important to note that only one person in the sample felt that they had noticed any adverse relationship between their symptoms and the act of smoking. There was nothing other participants had seen or felt which said to them that smoking was doing (MS related) damage. Coupled with their ignorance about the evidence we presented to them, smoking as a risk factor had remained below their radar.

Elevating the discussion to talk about the arc of disability (rather than day to day symptoms) and pointing to the fact that the harm done over time is hidden, did disarm some people’s objections that smoking was not impacting their MS. The evidence we were asked to use to support the “hidden harm” message was the fact that smoking can cause lesions to grow in size and/or number. For some this had power because the lesion is the marker of MS’s progression and having more or bigger lesions (like greater disability) is to be feared. However, the power of this message was not universal. Those whose lesions have not progressed were able to reject this information as not applying to them and their MS. A judgment will need to be made about how to use the connection between smoking and lesions. The recommended draft messaging approach proposed retaining the concept of hidden harm without specifying lesion progression. Should it be possible to say that smoking can damage the myelin sheath, this would be impactful. The sheath, like the lesion was well understood by people with MS and damage to it – hidden from view – would be regarded as alarming. If it is possible to link smoking related damage to further compromise of the immune system in people with MS, that too would be advantageous. Again, such links between the disease and the body were generally well understood by people with MS in the study.

It proved helpful in refining the propositions to communicate that the evidence linking harm to people with MS who smoke, is recent evidence. Stressing this fact made those who were open minded feel more receptive by reducing the risk of guilt or indignance that they had not be able to act sooner (and that HCPS had not prioritised this messaging).

People with MS reacted badly if they felt singled out or judged by the messaging. They needed affirmation that giving up smoking is difficult. Moreover, it proved better to calmly communicate

the specific MS related risks rather than explicitly communicate the general truth that people with MS face additional risks if they continue to smoke. Having MS is already a lot to cope with without undermining motivation with perceived pressure or blame for being a person with MS who smokes.

Stopober was viewed as an opportunity to commit to giving up smoking on a particular date and with encouragement and support. It was not as effective a driver to quit as a loss framing approach. However, some people who needed to boost their capability, felt it might provide the support they needed – especially if they were amongst the sample who were isolated, lacking in motivation and self-confidence. For those whose partners smoked, an issue could be getting them to quit too. Stopober provided a way to invite those partners to join or, alternatively, a way a smoker with MS could get extra support outside their unsupportive home environment.

The recommended proposition emerging from the research combined a loss framing approach with news and details about the Stopober. The loss framing approach was designed to raise awareness of the adverse links between MS and smoking and urge action to quit. Support messages were that “everyone with MS” needs to know that smoking is a hidden harm which “can speed the progression of disability” and “make your MS more active” and that “one study found that quitting smoking could delay the onset of secondary progressive MS by as much as eight years. So, there’s no time to lose. For help and support, go to [nhs.uk/Stoptober](https://nhs.uk/Stoptober)”

The information was surprising and sometimes shocking to many people interviewed. Care must be taken as the campaign is developed, to consider how people with MS might access the detailed clinical research evidence should they want it and how they might get emotional support or access assistance with quitting from HCPs.

Many people presented as very defensive about their smoking habit. It would seem unlikely that these individuals would seek out resources specifically aimed at them. Yet they were part of the target who needed to understand the basic facts about MS and smoking. This suggested a campaign which aimed to reach them in a wider context than merely a dedicated smoking website page or forum.

The findings of the research made it clear that the campaign was needed, given the lack of awareness of the risks of smoking with MS. The recommended messaging was designed to boost motivation by focusing people with MS on the frightening risks they face by continuing to smoke. Stopober provided an opportunity for change and a boost to capability. Further analysis using the COM-B model also recommended that HCPs be targeted so that a system response to the risks of smoking with MS could be triggered. Without the active participation of neurologists and possibly MS nurses in communicating risk, smokers with MS would lose opportunities to hear the stark facts they needed to boost their motivation to quit.

### 3 Detailed findings

#### 3.1 Characteristics of the sample (smoking behaviour)

The following table shows the smoking behaviour of those in the smoker and quitter samples

Table 2: Smoking Characteristics	Smoker (19)	Ex-smoker (8)
Age started smoking:		
under 16	13	5
17-18	3	3
18-24	3	0
Age now:		
25-34	3	1
35-44	4	0
45-54	9	4
55-64	2	1
65+	1	2
Smoked for:	(to date)	(until quit)
6-10 years	2	1
11-15 years	0	0
16-20 years	2	3
21-25 years	2	1
26-30 years	4	0
31-35 years	5	1
36+ years	4	2
Number of cigarettes a day smoked:	Currently	When quit
5-10	4	3
10-15	4	1

15-20	8	2
20- 25	1	0
26+	2	2

The majority of those who smoked or had quit started smoking in their teens. They were unanimous in the belief that peer pressure was the reason why they started, with a number also saying that their parents smoked and that this was the environment they had been raised in.

*"I was raised in a cloud of smoke"* (Female smoker aged 58. Diagnosed with RRMS in 2008)

Given their age now, this meant that all but one of the quitters and all but two of the current smokers had smoked for over fifteen years; with nine of the smokers having done so for over thirty years (and thirteen for over twenty-five years). Whilst the number of cigarettes they smoked a day now varied from five to forty, eleven of the smoker sample smoked at least fifteen if not twenty a day. This information suggests a smoker sample with a long term habit. They were individuals who had resisted or not managed to successfully respond to smoking cessation messages over many years. This had implications for their attitudes to quitting and to their smoking habit, which made smoking cessation messaging challenging. This will be covered within the barriers to giving up smoking section (3.4) and also explained the responses of some individuals to our messaging propositions (section 3.6)

### 3.2 Quit attempts

Everyone in the smoker sample had attempted to quit at least once, with most attempting to quit more than once. Quitters rarely managed to quit on the first attempt. Methods used varied as the table below shows, and most people had tried more than one method. We would not regard these figures as completely accurate because we feel that smokers underestimate or are vague about the number of quit attempts they have made. Our hypothesis is that this is part of a pattern of recall which is quite defensive in relation to smoking habits. We imagine people underestimate the number of cigarettes they smoke daily and may also "forget" unsuccessful quit attempts.

Table 3: Methods of quitting	Smokers (19)	Quitters (8)
Use of NRT (at least one attempt)	6	4
Champix or "tablet"	2	2
Smoking cessation group	3	1
Cold turkey (at least one attempt)	8	5
Cutting down	3	
Pregnancy	3	1
Vaping (usually instead of smoking but occasionally to cut down)	7	4
Hypnosis	2	
Allan Carr method	2	

The sample of quitters was very small (eight). Five went "cold turkey" on their successful quit attempt; one used NRT (gum and then normal chewing gum) and two used Champix. One of this group quit smoking and took up vaping instead of smoking (having taken it up when he quit). He described his HCPs as "not very happy about this" but he and they decided that it was better than smoking tobacco (in terms of general health).

The following themes emerged amongst smokers and quitters which will be explored more in section 3.4 when we discuss barriers to quitting:

- Vaping attracted interest from some current smokers. A number had tried it or considered it as a means of stopping smoking, often encouraged by friends or family who were ex tobacco smokers and now vapers. One quitter had successfully quit smoking and now vapes instead. For others there was uncertainty about the long term impact of vaping. Some had not found vaping a satisfactory alternative to the cigarette smoking habit. It "felt" different to hold an e-cigarette and/or they had experienced difficulties getting the dosage right.

- NRT was often mentioned as an unsuccessful method of attempting to quit smoking. There was mention from a few individuals of allergy to patches. Others mentioned the gum as “too strong” causing them to be unable to sleep or being too unpleasant to chew.
- Where smoking cessation clinics were mentioned, recall is that attendance was a “long time ago”. Two recent attempts to get help in this way had seen individuals being told that the clinic or a smoking cessation service through their GP were not available (with one individual not receiving any response to letters from her MS physio asking that she should be supported in giving up).
- Importantly an MS diagnosis or symptoms were rarely a trigger to a quit attempt or a successful act of quitting.

### 3.3 Why did the quitters quit?

The following table shows the reasons behind the eight successful quit attempts of our ex-smoker sample. NB. All our quitters were recruited on the basis that they had quit smoking on or since their MS diagnosis. In discussion with the MS Society we decided not to mandate that they had given up smoking because of their MS diagnosis. At the time of this research the Society had little insight into what impact, if any, a diagnosis of MS would have on smoker habits and did not want to assume a connection between a diagnosis or worsening symptoms/disability and quit attempts.

Quitter description	Reason for quitting smoking
<p>1. Male. Diagnosed with RRMS aged 23 in 1979. Took up smoking before he was diagnosed, aged 17 and quit aged 37. He is now 64 and his MS is “not very severe.” He has some balance issues and numbness in hands and feet but worked full time until recently as MD of a small marketing agency.</p> <p>Felt better after giving up – he had grown up. A sense of improved self-respect. Feeling better physically only came after he gave up drinking and eating so much twenty years later.</p>	<p>He quit when he became deputy MD of his company aged 37. He had spent his earlier adult life partying hard, drinking, smoking and taking drugs. His main reason for quitting smoking and drugs was that he felt he needed to grow up and change his lifestyle to respond to the promotion he had been given and be credible to his team. Never able to pinpoint that smoking affected his MS symptoms so did not see this as a major contributor to why he gave up and felt he might still have been in denial about having MS (at his quit point) which he “blanked” for a long time. Recently he has become much more active, lost weight and taken up exercise. But again, this was in response to a diagnosis of prostate cancer two years ago and refusal to operate on him until he lost weight – and not because of his MS.</p>
<p>2. Female. Diagnosed with RRMS in 2012 (aged 60). Took up smoking aged 19 and quit two years ago, aged 64. Smoked 30-40 a day throughout that time. Problems with blurred vision and instability/balance and</p>	<p>Quit because of a stage three lung cancer diagnosis in 2016. She had fallen and fractured her pelvis and was hospitalised on very heavy painkilling medication when the diagnosis of lung cancer was made, so in effect she gave up in</p>



<p>strength.</p> <p>Cannot say she is feeling better given her illness</p>	<p>hospital by default. No one had ever said to her that smoking was bad for her MS and she was unaware of the possible links discussed in the interview. No quit attempts in response to MS</p>
<p>3. Female. Diagnosed with RRMS in 2010. Took up smoking aged 16 and quit in 2012, aged 43. Smoked ten a day but could go through 20 on a night out. Unable to walk.</p> <p>Feels better. Sense of smell has returned. Fewer coughs and colds. Has more money.</p>	<p>Quit in a cold winter standing coughing on her balcony. Subject to lots of coughs and colds. MS neurologist mentioned giving up smoking to her on diagnosis "and then moved on". In contrast, diabetes consultant mentioned it often (she is Type 1) but she didn't pay attention to him either. Felt it took her a long time to come to terms with having MS and pushed it to the back of her mind. Did not think about links to smoking and did not know about them (but even if she had, her experience of being "nagged" by diabetes consultant and ignoring him, would suggest that knowing the adverse effects on MS would not have motivated her to quit)</p>
<p>4. Male. Diagnosed with RRMS in 2001. Started smoking aged fourteen and gave up aged sixty in 2010. Smoked ten a day towards the end of his habit. Used to smoke the "occasional joint" and that stopped too as he rolled it with tobacco. Mobility and speech difficulties</p> <p>Glad he has quit. Breathing better. Easier to practice the mindfulness his neurological psychiatrist has prescribed which he does find helpful ...easier to do the breathing now! Appreciates not being "tied to smoking" - i.e. has broken the habit</p>	<p>Just decided to give up. Wasn't enjoying it any more and smoking half a cigarette and putting it out. Financial reasons featured too as he had given up work due to MS. Neurologist did mention he should give up on diagnosis, but he (participant) said, <i>"that will be hard, and the neurologist agreed and that was as far as it went"</i>. Did not accept a correlation between smoking and worsening of MS and had not thought about it before the interview. Not his reason for quitting</p>
<p>5. Female. Diagnosed with RRM in 2002. Stared smoking aged seventeen and gave up aged forty four in 2012. Smoked twenty a day. Balance issues, drops things and beginning to notice cognitive impairment. Cannot focus or find the right words to sue in writing or speech.</p> <p>Glad she has quit. So much more time. "I feel</p>	<p>Decided that she was wasting too much of her life smoking, "huddled in the garage" and her husband said he didn't believe she could quit. No one had ever mentioned a link between smoking and MS at all. On thinking about it in the interview she said that because cannabis is supposed to be good for MS, maybe she had never questioned that smoking per se might be bad for MS. Also, instinctively resisted "putting anything and everything" down to MS – can't live that way. She said that smoking</p>

<p>healthier. Not out of breath, I don't smell of cigarettes, my skin has changed, my teeth feel cleaner, I have more energy. So my appearance has improved - I am sure there are also good things going on in my body but I don't know what they are"</p>	<p>feels like one of those things.</p>
<p>6. Female. Diagnosed with RRMS in 2007 and quit on diagnosis. Had started smoking aged seventeen and smoked twenty a day for nineteen years (until age of 36). Retired from work because of chronic fatigue. Also numbness her hands.</p> <p>Glad she gave up. Hard to see any health benefits as she was just starting DMT treatment. Felt better psychologically – having got control over the smoking and stopped. Financial benefits</p>	<p>Although quit on diagnosis she did not quit because of her diagnosis per se. "I decided it would just be my luck to get cancer too, so I quit". Her neurologist questioned her decision to give up the day she began her DMT saying "are you sure you want to add to the stress of this by giving up". He had previously said that smoking could not have contributed to her getting MS, so she didn't really feel there was a direct link because of his attitude. In stark contrast she believed that changing her diet and seeing a nutritionist has a direct link to how her MS responds. She said she visualises the food going into her body and an eraser "rubbing away the lesions in her brain" - she knew this could not happen but regarded it as part of her self-coaching to eat well -and imagine it "doing wonderful things inside"</p>
<p>7. Male. Diagnosed with RRMS in 2014 and gave up at that time. Had started smoking aged 13 and was forty six when he stopped. Smoked forty a day for the last fifteen years of his smoking life. Experienced fatigue and has 70% vision. Numbness and cannot feel under his feet. Suffers the "MS hug" which is very painful</p> <p>Glad he gave up but now vapes instead. Never felt unhealthy through smoking (his lungs were always apparently as efficient as those of a non-smoker) but appreciates a return of sense of smell and not smelling of smoke</p>	<p>Again, although he gave up "on diagnosis" it was not because of his diagnosis. His neurologist thought he had suffered a series of strokes and told him it would be life threatening not to give up, so he did. It then emerged that he had MS and not strokes, by which time he had quit. His MS neurologist did say she would not start him on his DMT (Tecfidera) if he started smoking again. This did stop him starting in response to his diagnosis, but he took up vaping instead. Importantly he wondered whether getting the advice about the DMT and smoking alone would have stopped him if the stroke misdiagnosis had not occurred. He was not sure. A stroke is life threatening and can promise instant disability. MS is a stressful diagnosis and everything that can happen is so much less certain (than the stroke impact).</p>

<p>8. Male. Diagnosed with RRMS in 2016 and gave up then, aged 26. Had been primarily a social smoker since the age of sixteen, often not smoking for days until smoking heavily on a night out. Mostly now symptom free after blurred vision and tingling which provoked his consultation and diagnosis.</p> <p>Always felt he was a social smoker so doesn't miss it. Feels better - more alert, energy levels higher. "Smoking and the body don't mix. It's not a good thing that's entering your body...why continue to smoke at all if you are diagnosed with MS?" ..... "You don't want other things thrown into the omelette"</p>	<p>He had a "weird" experience a month before diagnosis. He smoked a cigarette and as he did so, he felt his head go numb on the skin and then felt "<i>burning pinpricks across the top of his head</i>" and then his vision became blurred. Gave up smoking there and then and a month later was diagnosed via optic neuritis and tingling symptoms with MS. It has happened again since then but less severely, when he walked past a very large group of smokers. He said he was sure of the link between smoking and MS symptom severity because of his experience, although neurologist never asked him whether he smoked on getting his formal diagnosis.</p>
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The interviews with the people with MS who have quit smoking suggested that:

- MS was not the primary motivation for them to give up smoking (either on diagnosis or subsequently)
- Indeed, two individuals doubted whether they would have given up "on diagnosis" rather than at the time of diagnosis if information about MS and smoking had been more actively put to them. Both had given up around the time of diagnosis but for other reasons. They concluded that the threat of strokes or cancer (as mentioned) appeared more frightening and tangible than the threat of the adverse impact of smoking on their MS.
- Only one participant (8), directly attributed giving up smoking to a diagnosis of MS, having experienced MS like symptoms which were exacerbated by smoking a cigarette in the run up to his diagnosis.
- Everyone else interviewed gave up smoking for non-MS related reasons – either triggered by other adverse health events or reasons any smoker could use.
- Awareness of the risks associated with smoking for the person with MS was low. No one in the quitters' sample was able to say why and how MS might be impacted by smoking (prior to being given some information in the interview). There was a vague feeling that if smoking is bad for the health it is bad for MS, but no specific knowledge was forthcoming.
- Our sample reported that their neurologists mostly did not mention a reason to quit on diagnosis if the subject was raised at all. Those who referred to smoking were more likely to advise that "this is not the time to quit" (three individuals). Only one neurologist in 2014 tackled the subject actively, prompted specifically by discussions about starting a DMT and needing to avoid taking up smoking again in order to be allowed to do so (Tecfidera).

- All the quitters reported that they were glad they had managed to give up.

We have considered whether the individuals in the quitters' sample are consciously or unconsciously downplaying the role that concerns about their MS might have in motivating their decision to quit. We do not think this is the case:

- The interview with each individual progressed smoothly from discussion about smoking habits to exploration of reasons to quit and no one (apart from participant 8) raised the subject of MS and smoking at all until prompted by us to consider it. It was not top of mind as a reason to quit.
- No one in the quitters' sample knew why it was inadvisable to continue to smoke with MS.
- The lack of awareness and understanding of the risk and impact of smoking on MS was mirrored exactly in the findings from current smokers. Hardly anyone in the total sample of twenty seven demonstrated any awareness or knowledge. Two individuals, more recently diagnosed, knew that smoking can hasten the progress of their MS, because they had been told this by a neurologist.
- Giving up smoking did not (in this sample) come as a result of any knowledge around MS and smoking – knowledge which those who continue to smoke in the sample, do not have.
- The subject of smoking did not seem to be a high priority for neurologists. It was not reported as a factor in motivating quitting or thinking about quitting. There is an indication in our small sample that this priority may be changing for those with a more recent diagnosis, but we cannot say so conclusively. MS nurses generally did not seem to raise the subject with their patients.
- Response to the detailed information given in discussion and/or in the draft propositions genuinely came as a surprise or shock to nearly everyone in the sample. In advance of seeing the propositions, participants guessed that they should quit smoking with MS because smoking is bad for your health or maybe (when pressed a little) that the chemicals in smoking might be bad for the immune system and MS is a disease of the immune system.

### 3.4 Barriers to giving up smoking

The information in the report going forward is primarily from the smoker sample. Where indicated, we have also used feedback from quitters, who in many respects were similar to those who continue to smoke, in their attitudes towards messaging about smoking and MS.

Barriers to quitting fall into a number of categories:

- Smoker and societal attitudes towards being a smoker
- The binds and benefits of addiction
- Fears associated with giving up (general)
- Ignorance of the (elevated) risks of smoking as a person with MS
- Smoking and the psychological challenges of being a person with MS.
- Lifestyle changes brought about by MS

- MS as a disease – a peculiarly cruel moving target
- System issues

### Barriers: smoker and societal attitudes towards being a smoker

Smokers with MS were speaking of themselves primarily as smokers (without the MS factor). It is important to recognise that because smoking and MS is not a topic on the radar of most participants, they had not adapted their view of themselves as a smoker to one which says, "I am a special type of smoker ... one with MS". Because many of them had smoked for many years before having MS or since having MS - without challenge, their presenting relationship with smoking was recognisable to anyone familiar with smoking cessation research. Having MS does bring additional barriers to quitting for some (see below) but they seemed initially less salient reasons to the individual smoker.

In the main, smokers felt guilty about smoking. They knew there were general health risks. They may have reported having a persistent cough or get many colds. Their children or partner might be asking them to stop. Only a very few participants in the research defiantly said that they enjoyed smoking and did not want to give it up. The majority said that there is nothing they would miss if they successfully gave up smoking (although the process of giving up smoking was viewed differently and could create fear and anxiety).

Smokers also felt embarrassed and self-conscious. They knew that smoking is so much less prevalent today than when they started, which made them feel embarrassed to smoke in the street. Several participants used the phrase "I feel like a leper". Smokers often really disliked themselves and felt shame, as a result of disliking their habit. They disliked the smell of smoke on their clothes which they said was "disgusting". They spent a lot of money they did not have on cigarettes they did not enjoy. If they had tried and failed to give up, they felt they "have no willpower" so were very self-critical. They did not like that they crouched in the garage in the cold smoking - wasting time and looking "pathetic".

*"I am beginning a new life and a fresh start on my own" - giving up smoking would be a bit part of that. I hate it. Its smells, it's disgusting, hardly anyone smokes now..... "it's not really the thing anymore"* (Female smoker aged 50. Diagnosed with RRMS in 2000)

Smokers, especially those who have a long-established habit and who smoked a lot of cigarettes each day, tried to distance themselves from their smoking by calling it a "habit" or "just a habit". They tried to feel that somehow it was not part of them, that they were not to blame – whilst simultaneously feeling negative towards themselves for continuing to do it. Many said spontaneously, "I don't even like doing it – I don't know why I do it".

*"My brain would say, you haven't had a fag for a bit, so have one"* (Male quitter, aged 28. Diagnosed with RRMS in 2016)

*It's an addiction and a habit... I wouldn't really say I enjoy it" (Female smoker, aged 33. Diagnosed with RRMS in 2012)*

The result of this negative thinking and feelings of shame, was that the smoker could become defensive; beleaguered and sensitive to criticism even where none was intended. It proved very easy to trigger these responses with information and guidance which attacked the smoking habit and hence (they felt) the smoker. In assessing the response to the propositions, this backdrop will be key (section 3.6).

### **Barriers: the binds and benefits of addiction**

The comment that smoking is "a habit" is acknowledgement that it is an addiction. Smokers readily understood that they associated cigarettes with certain times of day; occasions; people or moods or even that they divided the time available to them and punctuated it with regular cigarettes. Those who smoked more cigarettes tended to be those who use cigarettes to combat boredom, isolation and/or stress or who had no practical reasons (i.e. a workplace ban) to stop them lighting up. Other triggers to smoke (more) mentioned were nights out; alcohol and the company of smoking friends or other social moments where smokers meet together. Living with a smoker was cited as a reason for smoking more. In that situation, cigarettes felt sociable rather than anti-social.

*"It's hard to stand between two smokers at a BBQ or whatever and not smoke". (Male smoker aged 54. Diagnosed with RRMS in 2013)*

Smokers said they associated smoking with certain times of day, such as a break at work; the journey to and from work in the car or a cigarette after a meal. In general, they were able to go longer without a cigarette when their environment did not enable them to smoke. Smoking at work was strongly associated with "taking five minutes"; or "stepping away from the stress for a while" or "having time out for me".

*"My instinct is to go to the car, get the tobacco, roll a cigarette, smoke it ...it's something to do when I take a time out (at work)" (Female smoker, aged 33. Diagnosed with RRMS in 2012)*

Others who saved smoking for certain times at the home could go for hours without a cigarette if they were occupied. They might smoke when they had a cup of tea or after dinner or first thing in the morning. Smoking is a ritual behaviour too. They reported that it gives you something to do with your hands. It gives you a reason to catch up with friends or colleagues who are smokers in the car park. It helps you focus before you say something or if you are nervous making a phone call. In general smokers readily agreed to the power of these ritual elements although they were not top of mind as "reasons for smoking", presumably because they were so habitual.

*"A lager and a fag it's just like fish and chips, they go together" (Male smoker aged 54. Diagnosed with RRMS in 2014)*

### **Barriers: fears about giving up – anticipated losses**

The fears about what they would lose if they give up related mainly to the act of giving up, not to a life where they had successfully given up. Most individuals said they wished they had not started smoking. Many felt they did not enjoy it and one person even called upon the government to ban smoking tobacco as the only way she felt she would quit, though desperate to do so. Giving up was considered with apprehension. The losses they anticipated were that they would become very anxious or stressed; that they would be bad tempered and not be able to cope with life or with sudden adversity. They also knew from previous quit attempts that they might miss the break from work afforded by the smoking shelter (and might still go there even if it was not to smoke). They feared that time might really drag, that they would have nothing to occupy their hands or steady their thoughts. Some women have tried to give up before and gained weight so feared that this might happen to them again. A few people said that giving up was always on their mind and they said they woke daily, resolved to quit but then felt very panicky and frightened and ended up smoking again within the hour. This intermediate land of “trying to give up or attempting to give up” appeared to be fraught with loss and difficulty for the smoker, making it hard to see the promised land beyond.

### **Barriers: lifestyle changes brought about by MS**

Adverse life events can push people into heavier smoking patterns. Divorce, illness in the family, or job loss were all cited as reasons why smoking could creep up on you or make you start again or increase your cigarette intake. After pregnancy a number of women who had stopped smoking in our sample, started again relatively quickly as life was stressful.

MS was a factor here for some smokers. Because people have been forced to give up their jobs or to work less or in a less stimulating environment, they reported that they became bored and isolated quite quickly. Insomnia (or insomnia brought on by anxiety and depression associated with MS) could also create a habit of using smoking to pass the time at night. A more sedentary lifestyle due to fatigue or pain; lack of working outside the home or side effects of some DMTs, can trigger weight gain which smoking (they believed) may help to curb a little. All these factors could make smoking creep up. All in all they felt that there was more time in a less satisfying or difficult day to get through and smoking helped with that.

*"The stress of being lonely" - dealing "with what MS has taken away from me" (job, mobility, driving). (Female smoker aged 51. Diagnosed 2008. Secondary progressive)*

### **Barriers: smoking and the psychological challenges of being a person with MS**

There is a psychological interplay between smoking and MS which participants did acknowledge but seemed less readily aware of than their general smoking habits and triggers. There were three main factors at work here: denial/defiance; stress relief and control. Participants differed in how much smoking was used to meet these separate needs.



In terms of denial/defiance, some saw (often in hindsight) that smoking had been an act of rebellion. Sometimes this was part of their reaction to their MS diagnosis when they denied for a time (sometimes a long time) that they had MS and defiantly continued with their lives as before or even stepping up their "bad behaviour". Smoking was seen as a very appealing weapon in that battle. Some people continued to see themselves as a rebellious person and smoking was part of that persona.

*"I don't like being told what to do (in relation to smoking and generally) ...my rebellious side"*  
(Female smoker aged 46. Diagnosed with RRMS in 2013)

MS causes a great deal of stress to people struggling to manage its physical and mental impact (cognitive or psychological) and struggling to come to terms with it. Those who struggled saw smoking as a "crutch" to help them. They believed that smoking actively helped them calm down or destress. One individual who had learned mindfulness to help cope with her pain management, even smoked whilst practicing it to ensure her breathing was deep enough to relax her. The association between smoking with de-stressing had another insidious effect. Some people with MS believed that they needed to do whatever they could to reduce stress, so they reduced their work hours; stopped participating in stressful social events or very active sports. They saw smoking as an ally in this adjustment because they felt it helped to calm them down and manage their general stress levels. Giving up smoking would stress them, and it would remove their ally in managing stress which they knew in turn affected their MS.

*"I do cope with a lot of stress and anxiety but for me a cigarette calms me " "* (Female smoker aged fifty. Diagnosed with RRMS in 2000)

Exerting or experiencing a sense of control is a third need which some people with MS felt that smoking helps them maintain. MS takes away a lot of control from the body (and the mind). It inhabits the body. It is also very unpredictable from day to day and over time. Smoking was something which the individual could choose to do for themselves in defiance of their MS. It was seen as a freedom they had, to do what they liked to do, when they liked to do it. A cigarette was a consistent friend in an inconsistent world.

*"I have still not come to terms or accept my MS ... I have had so much crap over the last two years, you could write a book about it. Smoking is a kind of constant and it doesn't need to change. I can't control anything else"* (Female smoker aged 37, diagnosed with RRMS in 2016)

### **Barriers: MS as a disease – a peculiarly cruel moving target**

Another aspect of the relationship between smoking and MS is the "get out of jail free" card (as one participant put it), that it is very difficult to conclusively connect any symptoms or symptom changes to the effects of smoking. Everyone's MS is different. MS is also a disease, as several participants pointed out, where any little "twinge or stubbed toenail can be blamed on MS." Those who had grown impatient with being told "It's probably your MS" had developed a mindset where they were determined not to blame everything they experienced on MS, because they did not



want their MS to define them. Smoking did not seem to them to affect them adversely (and if it did how would they ever know, given all that goes on with MS?)

*"if they could prove I wouldn't get another relapse " "It's just whether it gets triggered in you ... or the next person" (Female smoker aged 43. Diagnosed with RRMS in 2014)*

Instead smoking helped them maintain a sense of personal identity which was not just about having MS. It is significant that only one person in the study (from twenty seven) could say that he had felt any adverse effects on his symptoms, of smoking. In contrast two participants said that they felt immediate effects if they drank too much alcohol - in the form of increased fatigue and pain the next day, but felt no correlation between smoking and MS. To use a colloquialism, creating a link between smoking and its adverse effect on MS felt like trying to nail a jelly to a wall for the individual person with MS.

*"I know where my muscles are and with exercise, what makes me feel right and what doesn't... but it has not come to my attention, I don't see the link. I wouldn't say that on the days I smoke more I feel worse. Alcohol does that ... on the days I have alcohol I feel worse ...more tired the next day...more pain and more pins and needles" (Female smoker aged 51. Diagnosed with RRMS in 2000)*

#### **Barriers: ignorance of elevated risk of smoking and adverse impact on MS**

As already described, awareness of the link between smoking and any adverse impact on MS was virtually non-existent in the sample. It is not surprising then that having a diagnosis of MS or living long term with MS was not cited as a reason to give up. Other health conditions with immediate catastrophic impacts may be enough of a trigger to quit. The threat or diagnosis of cancer or seeing cancer in a close relative might be enough. MS is not enough because the adverse association with smoking is not there and because the health risks are not tangible, substantial and well accepted or understood. Furthermore, a few participants who had been looking for information about managing MS, commented that diet and nutrition seemed to them to have a higher profile at the moment. In general, they did not feel that smoking and MS had been a topic with much coverage. One participant did point out that she would be unlikely to go hunting for it or to click on a smoking page link on a website. Her sense of defensiveness about smoking would inhibit her from doing so. On the other hand, over two hundred people responded to the Society's initial invitations to participate in this study, which would suggest some appetite for engagement on the subject.

#### **Barriers: system factors**

This subject of smoking and MS is not one which neurologists and MS nurses seemed to champion at diagnosis. This was reported as a very difficult time when smokers had so much to digest. It is likely, they felt, that if smoking had been mentioned and then glossed over, (or not mentioned at all), it was not going to be something they would rush to prioritise or even recall.

Where it was occasionally mentioned, the HCP might then say with best intent, that a diagnosis of MS was not the time to contemplate stopping smoking.

*"The pharmacy said (when getting her first lot of MS drugs together) "don't worry about giving up smoking now, you don't want to increase your stress levels" (Female smoker aged 43. Diagnosed with RRMS in 2014)*

This sympathetic approach provided a continued permission to smoke. Participants were sometimes surprised that smoking was not mentioned and then felt they have got off lightly. Two respondents admitted to not telling their neurologist that they smoked and as it has never been mentioned, they had not been challenged to quit. As we saw in our research into people with MS and DMTs, the influence of the neurologist and MS nurse can be critical if people with MS are to be given the best chance of helping themselves to manage their MS. As a source, the neurologist has unrivalled credibility. In the case of DMTs we found that people with MS generally sought advice and welcomed support from the person they viewed as the expert about drug therapy. In the case of smoking the response may differ. The defensive individual may be less primed to "hear" what is being said or may seek to find a loophole in the evidence he or she is given. HCPs would need to tread carefully and tactfully in putting forward the evidence. On the other hand, leaving the discussion to chance or advising people not to quit lowers the chances of those with MS who smoke getting the information they need – from a credible source they meet face to face.

There is some mention in this research that smoking cessation clinics and resources may be under pressure. Those who have mentioned them in the research (a small minority) commented that they used them some years ago and a participant trying to get support from her GP (via her physio) had not yet received any response at all, despite four approaches on her behalf. Another participant had the same experience of his neurologist writing to his GP to ask for support for his patient to quit, with no follow up from the GP. Those who had attended in the past (three participants in the smoker sample) commented that they were not keen to repeat the group sessions and one felt that the clinic was very much a one size fits all solution. However, the two participants who wanted help of this kind were frustrated not to get it and a further two participants mentioned that they were considering going to their GP to get help (and saw this as the obvious first port of call).

*"It's all very well the MS Society doing this (raising awareness about MS and smoking) but it's a responsibility of delivering messages that may affect a lot of people (and not getting the help would be stressful) - and stress itself is a factor and trigger in MS" (Female aged 51. Diagnosed with RRMS in 2000)*

### **Barriers: help to quit - product support**

NRT was reported as a problematic means of trying to stop smoking. More individuals reported problems with patches (allergies) or gum (unpleasant or too strong) than reported success even in the short term. Champix or other "tablet" seemed to be more successful, although once again our

numbers are too small to conclude anything other than the possibility that NRT may also be rejected because of a poor past experience or negative perceptions.

Vaping provoked some interest amongst smokers and one quitter was now a vaper, having smoked forty cigarettes a day for over thirty years. A number of the participants in both the quitter and smoker samples said they had tried vaping and owned an e-cigarette. The general feeling was that vaping would be "better" than smoking tobacco because it is less antisocial. Some also felt that vaping did not fill the body with chemicals like smoking did and that the nicotine hit was less powerful, maybe providing a better means of stopping smoking altogether. Others took a different view. Two people had read about vaping and "popcorn lung" which deterred them from taking vaping up. Others found vaping an unsatisfying alternative to the cigarette. They found it hard to get the right hit of nicotine and were unsure what to choose in the way of dosage level.

*"I have a vape when I can't have a cigarette. But it's a mindset change to stop and vape instead or to try to reduce it to 50:50. Vaping it's not the same ... the taste, the hit, the smell when you first light up is not there"* (Male aged 40. Diagnosed with RRMS in 2014)

Another participant felt that cigarette has a beginning and end whereas vapers just seem to vape continually which she disliked. Another did not like the e-cigarette and how it felt in her hand. In general, there appeared to be some optimism about vaping, tempered with uncertainty about how to maximise its benefits and whether in fact it is a safe habit to develop.

### 3.5 Benefits of giving up

Smokers in the main just wanted to stop. They no longer enjoyed smoking and they wanted to be rid of it. The tangible benefits of giving up they mentioned were as follows.

- More money – and for those no longer working because of their MS, this could be a particular benefit (although as they were still current smokers they obviously prioritised smoking, in some cases by moving to rolling tobacco from filter cigarettes)
- No smell on them or in their environment (although most did not smoke in the house even if they lived alone, unless they were too immobile to go outside)
- Time – (one person). The time she felt she could use if she did not smoke and did not leave her desk to trail out to the car park
- The possibility of fewer coughs and colds
- Pleasing their spouse, children or grandchildren and being a better role model to children/grandchildren.
- Feeling better about themselves (usually an undercurrent rather than something they explicitly acknowledged)

It is significant but unsurprising that no one in the smoker group mentioned any benefits of quitting that related to their MS (as they answered this question before seeing the propositions covering messages about MS and smoking related risks). Most paid lip service to the fact that

quitting would benefit their health generally, but they spoke with more passion about other benefits of quitting which seemed more tangible to them (as listed above).

### 3.6 Responses to the propositions (messaging)

The research exposed individual smokers to the propositions in two phases. The original intention had been to discuss the propositions with seven individuals; respond to their comments and then introduce revised propositions to a mix of some of these original participants and some fresh participants. In the event we decided to show the propositions to new participants at each phase. This was for a number of reasons. We wanted to maximise the number of people seeing them (fourteen in all). Revisions to the propositions were not major between stages (although we did introduce one additional proposition at this point), so we felt that the original participants may largely repeat their views. Finally, a number of individuals at phase one became defensive and entrenched in their existing views about smoking and MS and we felt that interviewing them again might only serve to further entrench them. We chose instead to get further insight into the propositions with fresh participants.

#### Phase one propositions

Two participants took part in an online focus group (transcripts attached) and the remaining five participants were interviewed on the phone. We had intended to run the whole phase as an online group but in general found that participants recruited for the research were less willing to take this option than being phone interviewed. In addition, a number of people who signed up to take part simply did not do so on the day and did not offer any explanation to our recruiter. Online research did prove successful for The MS Society when we used it in the previous DMT study. However, in the DMT study, the participants were recruited externally using Facebook and were given expenses to cover their time. They were aware that those expenses would not be forthcoming if they did not participate and presumably were confident about doing online research as this was what they opted in to take part in. In this case smokers were not given financial rewards, and many seemed (to our recruiter) to be unsure of their ability to take part in online discussions.

We exposed four propositions to the phase one sample. Each of these propositions took a different approach to messaging using behaviour change theory as set out in section 1.5 of this report.

- Loss framing
- Gain framing
- Personalisation
- Social norming

Overall, we would comment that there are some smokers who were very resistant to messaging or engagement on the topic of smoking and its adverse impacts. The sample in this research comprised individuals who have smoked for many years, many of them quite heavily. As already

reported, this group did have some MS related reasons for smoking and barriers to quitting. But most did not see themselves as people with MS who (therefore) smoke or in a special category of “MS smokers”. They saw themselves, like many smokers do, as beleaguered people who wished they had not started but were defensive about being attacked for their habit.

One individual described the focus of the research on giving up smoking as

*“Like pissing in the ocean compared to finding a cure for MS – why bother?” (male smoker aged fifty six. Diagnosed with RRMS in 2005)*

In reporting feedback on the propositions, we will acknowledge this group and their views but focus on the attitudes of those for whom the propositions provided some shift in motivation or challenge to existing beliefs. This is not quantitative research, so we do not know what percentage of smokers might be engaged by the proposed MS Society campaign. However, qualitative research does uncover different types of individual and can provide insight into how messaging will work for those whose minds can be opened enough to receive it.

**Every cigarette robs your brain of the capacity it needs to fight your MS**

Evidence shows that smoking makes your MS more active, causing more and bigger lesions in your brain. Smoking also makes it more likely that your immune system will produce antibodies that neutralise disease modifying therapies (DMTs), meaning that your drugs could stop working. Don't lose any more of your brain to smoking. For help and support on giving up, go to [nhs.uk/smokefree](https://www.nhs.uk/smokefree)

**1 Loss framing**

The key thoughts participants responded to were a) that you are giving your brain a hard time if you smoke (“every cigarette robs your brain”) and b) the association between smoking and lesion damage as everyone in the sample was aware that MS causes lesions on the brain (and also for some, on the spine). The conversation around MRIs scans with a neurologist is always about whether the lesions have grown in size and/or number, so this messaging tapped into that.

Where this proposition could provide an escape route for those not minded to engage, was in the fact that some individuals had seen no progression in their lesions over appreciable periods of time. If someone wanted to reject the invitation to consider a link between MS and smoking, this could be a means to do that. This response was common to both stages of the evaluation of propositions.

*“My neurologist says that I have not had any increase in the number of lesions I have had over many years and says that I might be in a wheelchair by the time I am 160 at this rate, so that just isn't my experience” (Phase one female, smoker aged 67 with RRMS since 1999)*

However, this approach was also capable of making a smoker stop and think. This might be someone whose lesions had progressed or someone who thinks that they have not progressed to date but may do so in future. It had impact because it was "scary".

*"It makes sense because at the end of the day MS is a degenerative disease.... Every time you have a cigarette, that's not oxygen you are taking in is it... It's the tar, the chemicals. You are starving your brain" so "every cigarette robs your brain" is powerful ... I've felt fine for the 10 years (since initial MRI) but maybe I have just been lucky so far ... OK so there has been no change in my last two scans over the last 2-3 years but the change over the original 10 years was a lot (in terms of lesions) ...so would another 10 years show more changes again?"*

(Phase one female smoker aged 41 with RRMS. Diagnosed 2016 but given MRI scan ten years before that, to investigate her vertigo – no MS diagnosis then)

The section on DMTs was commented upon less than the thoughts about starving the brain and lesion damage. Where individuals did comment it was to seek reassurance that their DMT was not impacted by smoking. We were able to provide this (given our knowledge of which DMTs were listed in our briefing) but it will be important for any campaign to provide readers with easy access to information about this, should they require it. There may be smokers out there who have not told their clinician they smoke and who have started taking or changed their DMT. In conversations reported between patients and their clinician, where the subject of smoking was actively raised (very rare in the study), the trigger was a DMT the neurologist wanted to prescribe.

Most participants in the research accepted or rejected the messages they are being given here at face value. There were a few very curious and sceptical individuals who wanted to see the evidence. We provided them with further links to the MS Society site to help them pursue the issue further. <https://www.mssociety.org.uk/care-and-support/everyday-living/smoking-and-ms> .

*"Is it the CO2 in the brain" that does the damage. I know that smoking can "furr the arteries" ... so what (specifically) does it do in my brain to cause bigger lesions? (These are) "sweeping statements"... I am a mixture of sceptical and curious at this point" (Female smoker aged 51 diagnosed with RRMS in 2000)*

It will be important to ensure that a depth of information is readily available for this type of person especially for messaging that is based on research into the impact of MS on the brain or the progression of the disease. It is worth stating that the general consensus from the research was that the MS Society is a reliable source of trustworthy information on subjects such as this one.

Two participants commented at this stage that no one (i.e. no HCP) had ever told them that smoking could impact their MS – over many years. This caused feelings of guilt - or anger that they have not had this information. Occasionally, individuals read this proposition (and the gain framing one) as if smoking might have been a contributory factor in causing their MS, which was a lot to take on board and might lead to self-blame.

We suggest (for further phases of message development) that the MS Society stress, if they are able to, that the information about links between smoking and MS is only recently coming to light (if this is the case). This may help individuals to realise that neither they nor their neurologists are to blame if they have smoked for many years and not been aware of the potential dangers in relation to MS. People with MS can be very fragile and anything that exacerbates a tendency towards self-blame should be avoided.

Recommendation (for phase two)

- Retain this proposition for further exploration.
- Stress that the research evidence to prompt this campaign has only recently come to light but that the MS Society now feel the time is right.
- Consider using a reference or source to allow those who are sceptical but curious to further explore the research evidence.
- Make sure that the information specific to DMTs which might be affected by smoking is readily available to the smoker with MS population

## 2 Gain framing

### **From the first smoke-free day, your brain regains some of its capacity to fight your MS**

Did you know that stopping smoking can reverse many of the smoking-related risk factors linked to MS? In fact, quitting improves the chances that you'll be less disabled and that your MS will progress more slowly. One study found that quitting smoking could delay the onset of secondary progressive MS by as much as eight years. So give your brain a breather. For help and support on giving up smoking, go to [nhs.uk/smokefree](https://www.nhs.uk/smokefree)

The response to this proposition was similar to the response to loss framing, in that the core motivation, for those it impacts, came from fear. In this case it was the fear that their MS would progress to secondary MS more rapidly or that it would get worse within the first phase.

*"Anyone with RRMS, your worst fear is the change to secondary progressive...eight years without secondary progressive ...from which there is no going back, I find this even more hard hitting in a way because of that thought ...to think if you stopped you could extra years before secondary progressive." (Female smoker aged 41. Diagnosed with RRMS in 2000)*

So, although the approach was inviting the reader to consider the positive gain of changing their habit (smoking), the impact and drive to do so seemed to come from being stopped in their tracks by a fear of what might happen if they did not. This approach did not mention lesions (and the specifics of harm to the brain). Instead it concentrated on what individuals could see and track for themselves – the progression of their disability. This is important because, as we have

seen when discussing barriers to quitting for people with MS, they did not feel that MS impacted their symptoms day to day. Nor did they feel they could make this connection easily given the erratic progress of MS and its symptoms. This messaging took a step back and invited individuals to take the long view. This can hit home as the message articulated a big fear – how their disability might progress with or without being tied to further lesion damage. For some it also rested on an undeniable truth – they had seen their disability progress from diagnosis – or even before that point.

This messaging also echoed a more general message that smokers are given, that from the first day they give up they can affect the damage done. This connection may be a useful one because the message about MS and smoking impact falls on ground already prepared by general smoking cessation messaging. Our smokers did see themselves as smokers first and smokers with MS second, so building on general smoking cessation messaging may prove to be effective.

*"I have heard that one day without a cigarette is enough to start reversing some of the damage caused, but I've never seen anything saying that it could help slow the progression of MS"* (Female smoker aged 31. Diagnosed with RRMS in 2011)

There is an onus here on thinking of the impact of this messaging on those with primary progressive MS, as it raised a spectre (of secondary RRMS) which does not apply to them.

*(Gain framing) "This is the worst one which could give false hope to people".* (female aged 51. Diagnosed with primary progressive MS in 2009)

Recommendation

- Progress this route to stage two
- Consider how messaging like this will impact those with primary progressive MS (in general)
- Again, consider a reference or source for the curious and sceptical

### 3 Personalisation

#### Bigger things to worry about?

When you have MS, you can sometimes feel that mainstream health advice doesn't apply to you. But, actually, if you have MS, it's even more important that you lead a healthy lifestyle. In particular, smoking can make MS more active, causing more and bigger lesions in your brain. So if you have MS, or you have a close relative with MS, the MS Society recommends that you do not smoke. For help and support on giving up, go to [nhs.uk/smokefree](https://www.nhs.uk/smokefree)

Response to this proposition helped to refine how the smoker with MS sees the relationship between risks of smoking in general and risks around smoking with MS. It was not so much that



they did not think that the health risks of smoking apply to them. In many ways these are the risks they did know about. All seven of the participants in this phase one exploration, said they knew that smoking is bad for the health and that it is probably bad for MS too. What they did not know about were the specific reasons why smoking could be bad for people with MS.

The idea of MS becoming “more active” was a useful phrase. Once again, the lesion damage support can be effective and motivating or it can be rejected as something which “does not apply to me”. We concluded that it might be helpful to think about the hidden harm that is going on in the brain for those who have MS, so that people with MS who smoke might be challenged to think about what might be going on in their brain, even as they do not realise it. This may close the get out clauses that says (for example) *“I haven’t noticed my symptoms getting worse, therefore they are not getting worse”*.

In addition, smoking is an example of something that undermines a healthy lifestyle which is even more important if you have MS. To date other aspects of this messaging such as diet and possibly exercise, seemed to have had more exposure. One participant in this research took nine supplements daily and believed they help her manage her MS (and even that they have helped her MS stay in remission), but she smoked heavily each day. She was very resistant to messaging about smoking, but to date had not even been aware of the impact that smoking might have on her MS. For her and for others who do embrace a healthier lifestyle to help manage their MS, it seems an ethical decision to ensure they are at least aware of the smoking related risks too. As another participant put it

*“It’s even more important for people with MS “to lead a healthy lifestyle and smoking sits within that ...again it can be more active and more lesions can occur.”* (Male smoker aged 40. Diagnosed with RRM in 2014)

#### Recommendation

- Refine this proposition to focus on the additional risks of smoking with MS (as well as the general risks)
- Retain the messaging about leading a “healthy lifestyle and MS” as this is comms. currency which is familiar nowadays to those with MS - (with the caveat that “smoking; MS and a healthy lifestyle” have not been brought together before in communications).
- Focus on the “hidden harm” aspect of this proposition which communicates that it is easy not to realise the hidden but profound damage smoking can do to those who have MS. Consider other possible aspects of hidden harm such as myelin sheath damage if possible to tackle the fact that lesion damage is not perceived as something that applies to all.

## 4 Social norming

### Let's all quit together

This October, the MS Society is challenging everyone with MS who smokes, and everyone affected by MS who smokes, to join the hundreds of thousands of people making a quit attempt as part of Stoptober. We'll all be doing it together, so you'll have loads of support and encouragement. Plus, if you make it to 28 days, you're five times more likely to stay smoke-free forever. Which is good for you and good for managing your MS. To join in, go to [nhs.uk/Stoptober](https://nhs.uk/Stoptober)

The general response to this proposition in both stages of the research was positive. One conclusion might be that this was because this approach was less challenging and less confrontational – less based on “fearmongering” (as one participant describes the gain and loss framing approaches) and so is easier to nod to. It is notable that no one in the study had used Stoptober to help them quit (but then not all were aware of it). When pressed, those in the first stage who did not reject the propositions outright tend to pinpoint loss framing or gain framing as more persuasive than Stoptober, but some did feel that it might offer them some support to give up. This does not mean that the approach will be effective for all. Not everyone wanted to give up as part of a group. Many smokers said they would give up when they wanted to and saw even this encouraging approach as “putting pressure on them to quit”. Some smokers see judgement even in the most encouraging and inclusive language.

*"I'd rather just quit by myself if I did, trying to quit with other people is too much pressure and would probably just make me want to "cheat" more"* (Female aged thirty one. Diagnosed with RRMS in nnn)

However, this approach can address barriers for those with MS who smoke. Those with MS who live alone and/or who have given up work because of their condition will experience higher levels of social isolation. They and others may also experience rising levels of depression and anxiety, leading in some cases (including individuals in this sample) to consider or attempt suicide. Feelings of hopelessness and resignation can flourish. In such situations, smoking is a habit which can become very embedded. More time is available that has to be filled. Less is available that the smoker feels is “for them” and something they can rely on. Pointing the finger at them and telling them that smoking is bad for them can be counterproductive and increase their feelings of shame and self-blame.

*"If people are feeling bad then telling them to give up smoking - they know. It can make them feel bad too. Practical help would be better on how to give up."* (Male smoker aged 57. Diagnosed with RRM in 2014)

For them Stoptober might provide a more inclusive, positive approach to help them quit. They imagined a series of encouraging texts or messages to help them keep going and make them feel part of something. They suggested including some way of producing milestones they could tick

off (in tandem with the message that 28 days smoke free can increase your chances of being smoke free substantially)

#### Recommendation

- Retain this proposition. The positive, supportive and inclusive approach may have a role to play especially for those smokers with MS who feel very hopeless, vulnerable and socially isolated. Whilst there are those who still hear pressure of judgement in this approach, there are others who respond to the friendly tone and invitation to join in with something.
- Consider acknowledging that each smoker has to give up when the time is right for them and position Stopober as an opportunity to set a date and do this. This may add to the empathy of the approach as people with MS who are socially isolated need drawing in gently and kindly.

#### Phase two propositions

The propositions were refined in line with phase one recommendations and then discussed with seven new participants in telephone interviews. In addition, the MS Society made some minor adjustments to the propositions based on further consideration of the wording. Reasons for this are covered within the findings for each revised proposition below. A new proposition was introduced which explored a connection between stress relief and people with MS who smoke. This was a theme that emerged in stage one of the research and further mentioned in the background discussions with participants looking at the original propositions. We wanted to be able to fully understand this as a barrier to quitting smoking for people with MS and to see whether it could be challenged head on.

#### 1. Loss framing revised

##### **Every cigarette makes it harder for your brain to fight MS**

Evidence now shows that smoking makes your MS more active, causing more relapses and disability and bigger lesions in your brain. Smoking also makes it more likely that some disease modifying therapies (DMTs) work less well. Don't lose any more of your brain to smoking. For help and support on giving up, go to [nhs.uk/smokefree](https://www.nhs.uk/smokefree)

The MS Society altered the specific wording around DMTs and their effectiveness for people with MS who smoke, to be a more accurate reflection of the evidence. The headline was also changed from "Every cigarette robs your brain of the capacity it needs to fight your MS" to "Every cigarette makes it harder for your brain to fight MS". But at the same time the link to "disability" was made explicit in this proposition. The phrase "evidence now shows" was a response to the

recommendation to stress that the evidence base cited here is recent (so that smokers did not feel guilty that they had not acted sooner).

Responses to this proposition remained similar to phase one – in that some smokers rejected the evidence base and reacted against being told to stop smoking (as they saw it).

*"My lesions have not increased. We are in a good place basically. I can't walk well now but having no new lesions is a plus, so this is not my experience. I credit the drug (Tysabri) with it (i.e. holding back lesions)"* (Male smoker aged forty five. Diagnosed with RRMS in 2006)

*"They are telling me to stop smoking and I am going to decide when I stop"* (Female aged fifty. Diagnosed with RRMS in 2000)

However, this proved a thought provoking message for some – especially inclusion of the spectre of disability. Where some individuals feared disability in the future or had experienced relapses and progression of their MS, the proposition had resonance. The following participant had a very recent diagnosis and knew she should quit smoking because of her background as a nurse and the advice of her neurologist who *"has fixed me with a long cold stare."*

*"Makes people think they are going to get worse. And it's the thought of getting disabled. I have seen someone with the second phase of MS and it's not good. I don't want to get to that point."* (Female smoker aged 25 diagnosed three months ago (2018))

Another participant felt she should print this proposition off and stick it on her fridge. She was someone who reported thinking daily about quitting and had cut down a lot in recent years. She attributed the impact of this proposition to *"the scariness of it"*. Although she did not have new lesions emerging, she reported getting many relapses and felt her MS was progressing (Female smoker aged 49. diagnosed with RRMS in 2009)

The message around DMTs (which now no longer mentions the immune system producing antibodies) were less salient than the general messaging around lesions, disability and relapsing. It remains important to communicate the information about DMTs given that a number of individuals in this research had changed their medication during the course of their disease progression, but the proposition worked powerfully without this thought.

In a general sense, the loss of the mention of the immune system (compared to the phase one version of this proposition) could be seen to weaken it, because most people interviewed do understand that MS is a disease of the immune system and can relate to the idea that further attacks on that system are not a good thing for those with MS. They sometimes commented that smokers who had a lot of coughs and colds as a result of their smoking, might also be putting extra unwarranted pressure on that immune system. If it is possible to link smoking related damage to further compromise of the immune system in people with MS, that would be advantageous.

Although the proposition now said that “evidence now shows”, we feel that this aspect of the communication might benefit from being further amplified to explain why the campaign is being launched now. Most of these participants had never heard about a link between smoking and MS and may wonder “why now” or “could I have done something before and why didn’t I know?”

## 2 Gain framing revised

### **From the first smoke-free day, your brain has a better chance to fight your MS**

Quitting improves the chances that you’ll be less disabled. And it can also slow down how fast your MS gets worse. One study found that if you quit smoking it slows down how soon your relapsing MS became secondary progressive MS by up to 8 years. So give your brain a breather. For help and support on giving up smoking, go to [nhs.uk/smokefree](https://www.nhs.uk/smokefree)

Mentioning the specific figure that the disease progression can be slowed by eight years can be very powerful. This statement gives those who become open to this messaging a strong positive motivation to quit, albeit one based on evoking a sense of fear.

*"It's a bit of a reality check" ... "some food for thought". Because I have had MS for so many years now and they think I had it a long time before that. If I look back to how I was when I was diagnosed and the difference between then and now and then double that time (i.e. using the eight years going forward as well as back)" (Female aged forty six. Diagnosed with RRMS in 2013)*

The MS Society asked us to explore both the concept of “being disabled” and the concept of “how fast your MS gets worse” to see whether one relates to physical disability and the other to cognitive impairment and other symptoms. In practice disability proved the more salient and sobering concept – i.e. the one remarked upon more often in response to the proposition and conjuring up reduced physical ability/mobility. The notion of your MS “getting worse” was also often interpreted as relating to physical impairment. A general observation is that people were more likely to characterise their MS (when asked) in terms of physical symptoms – although a few did mention cognitive impairment. The latter tended to be individuals who were still working and who may have had a better yardstick for noting a decline (although this is merely a hypothesis from a very small sample). If smoking does have an adverse effect on “cognitive” ability in those with MS, it would need to be mentioned specifically (with ideas such as poorer focus, memory or concentration being unpacked). Our view is that disability (linked in the reader’s mind most readily to physical loss) is the most powerful word to support the overall loss framing and gain framing propositions. One participant did mention that the phrase “improves the chances you will be less disabled” was perhaps less accurate than the phrase “improves the chances that your disability will progress more slowly” as the former might suggest some degree of possible reversal which she knew to be out of the question.

"My left side is my weak side and I can't make that better by not smoking." (Female aged forty nine. Diagnosed with RRMS in 2009)

In both the gain framing and loss framing propositions we asked the MS Society if we could introduce a source or reference to increase the sense of authority and expert credentials associated with the claims made. This was due to the resistance of some smokers to believe the new and quite startling claims made in these propositions about smoking and MS – claims they had not heard before. For some this made it easy to reject the evidence as "them" coming with "new ways to try to frighten smokers because of their MS" and "just seems like they're grasping at straws to try find new ways to get people to quit". (Female smoker aged thirty one. Diagnosed RRMS in 2012 – phase one participant).

Because the MS Society intended to launch this messaging in social media, they planned to provide a link to support the claims made, rather than citing the source in the messages themselves. It was therefore important that we presented the propositions in the same way (i.e. without sight of a source or reference in the text). We used the MS Society logo in the slides presenting the propositions to increase the authority of the claims. This did seem to reduce the head on attacks on the information to a degree - because "they are the experts and so I can't disagree with what they say", as one participant put it. It did not change the mind of those determined to resist but was useful in confirming the expert status of the MS Society as the campaign source.

This information was quite shocking and surprising to some participants. In becoming familiar with the evidence about smoking and MS it will be important not to forget its power to disturb some people who read it for the first time and who might need more support than merely being invited to visit the [nhs.uk/smokefree](http://nhs.uk/smokefree) site. How those who receive the campaign messages might take their next steps will be important to consider.

### 3 Personalisation revised

#### **Why it's even more important that you give up smoking**

Everyone knows the health risks associated with smoking. But for people with MS, the risks of smoking are even greater. This is because smoking, makes your MS more active. You may not notice it immediately, but the damage is happening inside your brain. It can show up as more and bigger lesions in the future. So if you have MS, stopping smoking has extra benefits.

For help and support on giving up, go to [nhs.uk/smokefree](http://nhs.uk/smokefree)

The communication within this proposition was made clearer with the positioning of additional health risks for those with MS who smoke- over and above those we all know about. Response to the revised proposition suggested that this might be the most accurate way to introduce the subject of smoking to those with MS (who smoke). It is important because as we have seen, those

with MS did not know that there are specific risks for them and did not see their MS as a motivation in its own right to quit smoking.

*"I have never connected smoking and my MS. So, I want to know and learn more...but my MS won't stop me smoking, I will make me stop smoking"* (Female aged 50. Diagnosed with RRMS in 2000).

On the other hand, the headline "why it's even more important that you give up smoking" did seem, to a minority of participants, as quite accusatory. It will be important to discuss the risks as specific and to give the facts, without making smokers with MS feel even guiltier and beleaguered. There is a risk they may feel that you, the MS Society, thinks they are not capable of quitting without being singled out for extra attention and nagging. A kind of "go on, hit a man whilst he is down" response.

The concept of "hidden harm" was also explored here. This was included to acknowledge more explicitly that smokers with MS did not know about the damage smoking is causing and did not notice any tangible links between their smoking and their day to day symptoms. We had intended to add some information within this proposition; namely *"smoking can damage the nerves including the myelin covering around them"*. The intention was to see what might happen if we did not have to rely solely on lesion damage to support the hidden harm thought. On advice, this part of the proposition was not pursued because a direct link between smoking and nerve damage is not currently supported by the evidence base.

Thus some individuals were still able to reject the claims made, on the basis that their lesions remained stable. Despite this, the concept of "hidden harm" which could be introduced into the gain framing or loss framing propositions did have the power to disrupt some individuals' attitudes. It added weight to the gain framing proposition for the individual participant who suddenly looked at the existing and potential arc of her disability into the future, suggesting to her that much of what is happening was going on without her noticing it – literally because the damage was hidden and figuratively because she was pushing it to the back of her mind. It is on this basis that she said she would be giving herself a good talking to.

#### 4 Social norming revised

##### **We can quit together**

Most smokers want to give up, but it can be hard to find the right moment to do it. That's why, for many of us that smoke, this October is the best time to quit. You'll be joining the hundreds of thousands of people giving up smoking for Stoptober. And we'll be doing it together, so you'll have loads of support and encouragement. If you make it to 28 days, you're five times more likely to stay smoke-free forever. Which is good for you and good for managing your MS. To join in, go to [nhs.uk/Stoptober](https://nhs.uk/Stoptober)

Minor changes were made to this proposition to increase its empathy. The invitation to join Stoptober was now explicitly couched in terms of "we" and "us" and an acknowledgement that finding the right moment for you as an individual to decide to quit is important, was added. The fact that "if you make it to 28 days, you're five times more likely to stay smoke-free forever" was retained. Responses remained positive to the idea of the MS Society joining Stoptober as a means of raising awareness about this issue for the first time and persuading people to set a date:

*"If you do it on your own you can lose track... it's good to think you are not on your own" ... "Some people don't tell their consultant they smoke...it's embarrassing, and they know it's wrong and they are frightened of being judged so other ways to give up and admit to smoking (e.g. Stoptober) are good. (Female aged twenty five. Diagnosed with RRMS a few months ago (2108))*

But often this was about how good it would be in persuading other people (not me).

*"I might want to give up in November it's up to me" (Female aged fifty. Diagnosed with RRMS in 2000)*

The twenty eight day claim was again familiar to one of the participants and provided a way of looking beyond the day- to-day torment of giving up and focusing on the benefits of being smoke free.

One of the big barriers to quitting is living with someone who smokes too. This campaign is focused on the person with MS and so we have removed references to others in all propositions tested. However, it remained the case that the presence of another smoker was reported as a deterrent to stopping and a deterrent to staying as an ex-smoker. As one participant pointed out, it is so easy to get rid of your cigarettes but then pinch one from your husband and start again.

In this sample the participants who mentioned a partner who smoked seemed very uncertain that their partner would quit to support them.

*"It's like a teaser, it draws you in but for me personally my husband smokes, how can I stop him smoking. He is not giving up. How can I convince him to go in the garden every time?" (Female aged fifty one. Diagnosed with RRMS in 2008)*

Stoptober might issue an invitation to partners of those with MS, to join them in their quit attempt. On the other hand, it might be the case that inviting people with MS, who live with a smoker, to join others outside their home who want to quit, might help them resist the temptations of still living with someone who smokes.

Overall Stoptober felt like a positive initiative which could provide some very sensitive, often defensive smokers who expect to be judged, with an empathic support system to help them quit. On its own it appeared less motivating in encouraging people to seriously consider quitting than



the gain framing or loss framing options. It was effective, more of a means to an end (an opportunity to put into action a decision to quit) than a core call to action to quit

## 5. Smoking and the mind – stress reduction and smoking. A new proposition at phase two

### Do you sometimes feel you would be lost without your cigarettes?

People with MS can have to deal with a lot of stress and anxiety. You might think smoking helps you with the stress of having MS. But every cigarette is actually making it more likely that your MS gets worse. So, if you really want to reduce your stress, find a way to give up cigarettes. For help and support, go to [nhs.uk/smokefree](https://www.nhs.uk/smokefree)

This proposition was introduced to help us better understand the complex relationship some individuals have between being a smoker with MS and using smoking to cope with stress. Some individuals talked about needing to reduce their stress levels and calm themselves. They believed that this was important because stress could make their MS symptoms worse. Smoking they believed, helped them to be calmer and reduce stress.

In response to the proposition individuals could react quite defensively. The headline could be seen as quite patronising. For the individual, smoking was regarded as ally in managing MS. This might be breathing through the pain, with the help of a cigarette. It might be using smoking as part of a package of calming measures to manage the impact of stress on MS symptoms. (These could be measures such as reducing job hours or responsibilities, taking more rest and accepting the diagnosis rather than trying to fight it). Because smoking was seen as a friend in managing stress levels which might exacerbate MS symptoms, the assertion that smoking can make your MS worse could not win out.

*I don't think it's that it helps with the stress of having MS. .it helps me with the impact of that stress on my MS. I have accepted my MS and it doesn't stress me. But I turn to smoking in a stressful situation and stress does not help my MS" (Female smoker aged fifty three. Diagnosed with RRMS in 2014)*

For others, having MS was stressful and smoking simply helped them to have something for themselves which calmed them

*I do cope with a lot of stress and anxiety but for me a cigarette calms me ...it's the opposite to this" "* (Female smoker aged fifty. Diagnosed with RRMS in 2000)

For one participant the statement was true (in that she felt she managed to reduce her stress levels by smoking), but she found this approach much less specific and frightening than the loss framing approach she preferred, in which facts about why smoking makes your MS worse were set out.

The intention in the research was to explore propositions for people with MS which were not just reliant on generalised advice to all smokers about why they should quit. We removed from this proposition the assertion that *"some of the stress and anxiety you're feeling is actually caused by smoking. It's a symptom of withdrawal from nicotine, which each cigarette only appears, temporarily, to relieve"*. In conversation with two participants we mentioned this phrase, which they found interesting but still insufficient for them to break the belief that they managed the negative impact of stress on their MS better as smokers. This is a very difficult link to break. Our view from this research was that it is better in the first instance to introduce smokers with MS to the new evidence about why they should stop smoking than to try to confront head on such an entrenched belief that smoking can relieve stress. Linking smoking to disability, relapses and disease progression reframed the debate in ways smokers with MS are currently not aware of. These links challenged a core belief that "smoking has no specific effect on my MS" (and "I have never given a conscious thought as to whether and how MS is adversely affected by smoking").

### 3.7 Getting the messages out there

Two points are worthy of consideration. The first is that individuals reported that they tended to immerse themselves in googling and researching MS on diagnosis and then their researches tailed off. The second is that smokers in this study could be very defensive and some demonstrated with their responses to the propositions, that they were living in denial. This suggested that they might have little motivation to explore smoking and their MS, especially as no HCP was urging them to do so.

It will be important that this campaign lives outside the "learn more about MS and smoking tab" on the MS Society website and that it becomes a higher profile topic on social media which people with MS initially access for a variety of wider reasons.

In general participants felt that it was good that the MS Society was tackling this issue and raising awareness.

*"People don't talk about it on the forums ...they (The MS Society) should create a thread or a sticky on the forums because it's not really a taboo subject but it's not talked about on there either"* (Male smoker aged 40, diagnosed with RRMS in 2014)

### 3.8 Recommendations – messaging development

- There is a need to educate those who have MS and smoke as to the specific risks they face by continuing to do so. Currently awareness of the specific risks around MS is very low.
- Smokers can be extremely entrenched and defensive. We need to recognise that although the clear majority genuinely wanted to give up smoking, some will not be persuaded by messaging of this kind (or any kind) to do so immediately. We cannot know the longer term impact of raising their awareness of the facts, but doing so is an important first step, given current levels of ignorance.

- Even in the context of a hard hitting campaign, it is helpful if the tone of voice used avoids making smokers feel judged. It is important to state that the MS smoker evidence base is only now emerging (so they realise they could not have known about this before). It is important to understand that whilst people with MS face specific risks in relation to smoking, this campaign should not adopt a tone which makes them feel even worse about smoking than they already do. Saying there is even more reasons for YOU to quit risks this.
- The most impactful messages for those who do see a shift in their motivation, are gain framing and loss framing, with the important proviso that both appear to work by leveraging the fear people with MS have about their disability getting worse over time- either because smoking can accelerate the rate at which MS can become secondary progressive (the “eight year study”) or because it can make MS more active, leading to more relapses and disability.
- “(Rate of) disability” appears to be the most salient issue. It confronts the fact that people with MS do not see or believe that smoking can impact their day to day symptoms. Raising the discussion above symptoms - to the level of the arc of disability over time - is harder to dispute and can trigger their worst fears, as discussed. The mention of eight years as a specific marker is effective as a support to this approach.
- “Disability” seems to relate to physical impairment which is the most common way that people with MS describe their symptoms and the impact of MS over time. Fearing increased physical disability seems the highest top of mind issue.
- Cognitive impairment is generally mentioned less – in terms of symptoms and certainly in terms of fears for the future. We are not sure what this is the case (unless it is harder to gauge impairment over time, particularly in people who do not work or perhaps it just feels less catastrophic). Therefore, messaging about “cognitive impairment” due to smoking may be relevant (if made real and couched as “poor concentration” or “memory loss”, for example), but is not recommended as headline messaging. “Disability” is more effective.
- The other possible means of countering the fact that MS does not appear to “make my symptoms worse” is to introduce the notion of “hidden harm”. It is powerful to think that you may not realise what is going on in your brain if you smoke and have MS, but that over time damage that you cannot see, is happening. The firm evidences we are able to leverage, relates to lesions (size and proliferation). For some, mention of the risk of getting bigger and more lesions is scary and motivating. People with MS know that lesion development is the most visible sign of MS progressing. It is the subject of discussions with neurologists after each MRI scan. Unfortunately, for others the fact that their lesions have not grown or proliferated, means they can reject this messaging. Without being able to talk about myelin sheath damage (which is the other characteristic of MS that most people with MS seemed to understand in the research), this proposition becomes less universally powerful. A judgement will need to be made about whether the pros of using this as support to a loss framing approach outweigh the cons of letting some smokers off the hook who read it. Our recommended proposition does not include this support.
- The tone of the campaign messaging will be hard hitting. The facts which are frightening are not generally known to the potential audience. Care will have to be taken to think about how

those who are affected by what they hear or read will be supported to quit. Others may need support to research the subject in more depth if they wish to. Some may just need emotional support if they feel alarmed or upset. In addition, the recommended messaging approach may not be appropriate for those with primary progressive MS.

- Stoptober is not as effective an approach in creating motivation to quit in this sample as the loss framing option. However, it is, for some people whose life with MS makes them lonely, isolated and lacking motivation - appealing as an opportunity to find a way to quit. It will be important to personalise responses as far as possible and to provide positive but gentle encouragement and empathy, to a fragile group of smokers. They are very sensitive to feeling pressurised or judged. If this is what they detect in messaging, their motivation (and therefore their desire to use Stoptober as an opportunity) will diminish. The “28 day” claim is positive in that it helps them see beyond the fear and panic the spectre of giving up evokes, to the promised land beyond.
- Smokers with MS can live in homes with other smokers who do not want to quit. It will be interesting to explore whether and how to acknowledge this, in messaging about Stoptober to this target audience
- Starting a conversation about smoking and stress with people with MS is problematic. Smokers with MS want to reduce stress in their lives. In smoking they have an ally when MS takes so much away from them. Smoking relieves stress. Moreover, the idea of giving up smoking (as distinct from being successful ex-smoker) creates a sense of panic and raises stress levels. Confronting these beliefs and pointing out that smoking can make MS worse and that smoking adds to stress, tends to entrench them and make them feel more stressed about giving up smoking. We recommend that this approach is not pursued especially as there is much work to do to get MS related smoking risks across for the first time.
- Neurologists and other HCPs may be becoming more active in providing their patients with advice to quit smoking, because of the adverse effects smoking has on some DMTs. In general we found that there is a need to communicate with HCPs as well as people with MS if the system is to support the campaign messaging and provide consistency of advice. The role of MS nurses in providing smoking cessation advice is not clear from this research, but as reported by participants, they do not appear to do so.
- The subject of MS and smoking appears to be lower profile than discussions about MS and diet or possibly MS and exercise, amongst this sample. It will be important not to confine messaging to a smokers’ ghetto if this is to be changed. Because smokers can live in shame and denial, they may not actively seek out a website page aimed at them unless they are already determined to quit. This campaign will need to have an approach which gets the facts and messages out there to the MS community who smoke and who are ignorant of risk and currently low on motivation. It is encouraging that the call for participants for this research (on Facebook and Twitter) did achieve good levels of interest.
- Vaping is currently attracting interest in those wishing to quit tobacco. Uncertainty is reported about whether vaping is a better (i.e. less harmful) way of smoking than smoking cigarettes. Some report not being able to “get on with” vaping either because of the difference between

smoking an e-cigarette and a cigarette and/or because they find it hard to get the right level of nicotine hit for themselves. Smokers are looking for information and guidance about vaping and its possible role in helping them to quit tobacco.

### 3.9 Towards a proposition

On the basis of the recommendations we put forward the following draft proposition for the MS Society to take forward for the autumn campaign

#### **What everyone with MS needs to know about smoking**

We all know that smoking is bad for our health, but new evidence shows that smoking can also make your MS more active, which can speed up the progression of disability. You may not feel it with each cigarette, but the damage is happening inside your brain.

We know how hard it can be to give up. But this October, the MS Society is encouraging everyone with MS to make a quit attempt for Stoptober. You won't be alone – hundreds of thousands of others will be quitting – and you'll get lots of free support and tools to help you stay quit.

One study found that quitting smoking could delay the onset of secondary progressive MS by as much as eight years. So there's no time to lose. For help and support, go to [nhs.uk/stoptober](https://nhs.uk/stoptober)

#### 4. COM- B model applied to people with MS who smoke.

The following table summarises the findings of the research using the COM-B model to pinpoint barriers; suggest ways which might be found to increase capability and identify ways to engage with smokers and increase their likelihood of quitting smoking successfully.

Capability (Can people change/act?)	Opportunity (chance to change/act)	Motivation (do people want to change/act?)
<b>1. SYSTEM ISSUES:</b>		
<p>Is there a professional consensus supported by an evidence base, that drives neurologists to ask new patients about smoking and inform them of the dangers of doing so if they are a person with MS?</p> <p>The neurologist has the first opportunity to position the evidence as credible and a priority to newly diagnosed individuals who smoke.</p>	<p>A person with MS cannot act if they are unaware of the evidence that smoking may adversely affect their MS</p> <p>Neurologists do not always (or often?) raise smoking with newly diagnosed or longer-term people with MS. A missed opportunity</p>	<p>Some smokers resist/reject/try to undermine the evidence as they are not ready to quit and feel beleaguered and marginalised.</p> <p>Some smokers are receptive to the messages explored in this research and feel the evidence given provides them with added motivation</p> <p>A few smokers genuinely want more information (in depth) before they will take the evidence on board so MS Society resources on smoking may help build motivation and capability for them</p>
<p>This research suggests MS nurses do not ask people with MS about smoking. Do they feel it is outside their remit or might compromise their positive relationship with someone who might feel judged or criticised? Do they have time to do this?</p> <p>MS Society can raise awareness amongst HCPs and support this HCP approach (NB: other HCPs such as specialist physios)</p>	<p>A person with MS cannot ask for support if they are unaware of the evidence that smoking may adversely affect their MS</p>	<p>If the individual's relationship with their MS nurse is good (and if they have fairly regular contact with them – a capability issue), this might be a more empathic relationship to ask for help and build motivation through one to one support if the nurse raises it with them</p>

Capability (Can people change/act?)	Opportunity (chance to change/act)	Motivation (do people want to change/act?)
<p>If the person with MS is a long term smoker, the chances are they have smoked for years post diagnosis. Neurologist may never mention smoking risks at annual review (and may not know they smoke). Can neurologists be persuaded to review the smoking habits of longer term MS patients?</p>	<p>A person with MS cannot act if they are unaware of the evidence that smoking may adversely affect their MS</p>	<p>Those who have seen their MS progress since diagnosis may find the evidence about smoking progressing the speed of transition to secondary MS, powerful. (NB some newly diagnosed individuals are also receptive to this approach)</p>
<p>A DMT conversation or review may increase the likelihood of the subject of smoking being raised – given that smoking can potentially undermine the effectiveness of certain DMTs</p>	<p>Smoking is mentioned specifically in relation to MS and risks around DMTs as part of a protocol. Neurologist may insist the smoker quits before being given the DMT (where applicable)</p>	<p>Possibility that smokers feel less judged – they are being asked to consider quitting in order to maximise DMT effectiveness, not because they are a “bad patient.” May increase motivation to quit at this point.</p>
<p>HCPs shy away from smoking conversations with people with MS or say, “<i>perhaps this is not the time to quit</i>” (on diagnosis)</p>	<p>An opportunity missed or further thought needed about when the best time to broach smoking is with the individual who is newly diagnosed?</p>	<p>Motivation to quit is not encouraged. Permission to smoke is reinforced</p>
<p>Smokers are not taking the chance to ask HCPs about smoking and MS at appointments because they have not been primed to raise the topic for themselves</p> <p>Resources about the evidence and risks may build capability of the smoker to be proactive with HCPs</p>	<p>Raising the profile of smoking and MS as a topic (as has happened with diet and MS for example, according to some participants here) provides the opportunity to access the HCP and ask the questions.</p> <p>Resources needed to put this issue on the radar for smokers with MS (outside the HCP space)</p>	<p>If smokers want to quit resources and evidence can raise their determination to do so.</p> <p>Need to recognise that some people will want resources to help them approach an HCP for information and/or support whilst others will want to motivate themselves to quit entirely in private (through shame or desire to avoid added pressure to quit)</p>

Capability (Can people change/act?)	Opportunity (chance to change/act)	Motivation (do people want to change/act?)
<b>2. PROPOSITIONS (MESSAGING)</b>		
<p>Smokers can feel very helpless about the prospect of giving up smoking. Fear, panic and sense of anticipated loss undermine any sense that they can do it – that they have capability. So they remain self-critical and put off the date. Sensitive to any pressure or judgemental “nanny state” approaches</p> <p>Stopober can help them see the other side (<i>“If you make it to 28 days, you’re five times more likely to stay smoke-free forever.”</i>)</p>	<p>People with MS who have to leave their jobs or become increasingly immobile may become bored, under stimulated and isolated</p> <p>Stopober may help some individuals find an opportunity to join something and set a quit date – with or without a partner who smokes</p>	<p>Motivation to quit is undermined as smoking levels may creep up and smoking is used to fill the time and provide the smoker with something for them they enjoy (with no work place ban to stop them). If they live with a smoker this can be exacerbated.</p> <p>For some individuals Stopober may provide them with motivation (by becoming part of something) and boosting motivation to set a date. The expectation is that Stopober will provide them with empathic personal(ised) encouragement (by demonstrating understanding of their barriers and desire to quit)</p>
<p>How do smokers retain and capitalise on the boost to motivation they experience when taking part in this research interview and hearing the evidence? MS Society an authoritative source for them.</p> <p>Is there a more developed conversation that needs to be had with them:</p> <ul style="list-style-type: none"> <li>• Effective ways to stop smoking? (perceptions of NRT can be negative)</li> <li>• Reminders of the reasons to quit?</li> <li>• Regular encouragement?</li> </ul>	<p>Providing support to people with MS about the specific dangers of smoking with MS gives them the opportunity to act on their desire to quit (if they are motivated)</p> <p>Brings MS into their frame of reference as a smoker – before the interview their thinking had been around general health risks and smoking - not MS related health risks.</p>	<p>Some smokers are entrenched in their habit and resist the evidence. They are not ready to quit (even though they want to). Hearing the scientific evidence increases their sense of resistance and defensiveness.</p> <p>Other smokers feel that some of what they have heard in our propositions has raised their interest and ask for further information to be sent/or say “I am going to give myself a good talking to” ...feel more motivated to quit</p>



Capability (Can people change/act?)	Opportunity (chance to change/act)	Motivation (do people want to change/act?)
<p>The big picture to boost motivation and opportunity needs to be around communicating the adverse impact on MS of smoking.</p> <p>However, beliefs about stress relief have a special place in the psyche of some smokers with MS and fear of increasing stress is a particular barrier to quitting. Can capability be boosted with support to embrace other stress relieving activities and habits whilst quitting smoking (and beyond)? Acknowledging the specific fears of the individual with MS and the impact of stress on his/her disease symptoms</p>	<p>Opportunity for people to hear messaging that smoking does not relieve stress, quite the opposite ...but this is a hard barrier to overcome especially if you have MS and have anxiety and depression as part of your daily life. Challenging beliefs that are very entrenched.</p>	<p>MS is very stressful at diagnosis and beyond. MS reacts badly to stress in the person that has it. People with MS try to reduce stress. Smoking helps them do that (so they believe). Smoking helps them to feel calmer.</p> <p>Motivation to act on advice about smoking and MS can be undermined by beliefs about smoking relieving stress and conversely the fear/ panic engendered when thinking about stopping.</p>
<p>It can be difficult to receive this news and participants need support to their motivation. An explanation that says they will not necessarily be aware of what is happening in their brain may help to reduce possible feelings of guilt and self-blame about smoking with MS and boost capability.</p> <p>There is an ethical responsibility to consider the impact of this news on those who have MS and smoke and may be living with little support. Also, to consider what messaging might be appropriate for those with primary progressive MS</p>	<p>The fact that the harm is hidden but real, provides an opportunity to communicate that the damage may be being done even though the person is unaware of the risk and the impact. (loss framing focus) <i>"You may not notice it immediately, but the damage is happening inside your brain. It can show up as more and bigger lesions in the future".</i></p> <p><i>"... causing more relapses and disability over time"</i></p>	<p>Participants do not associate smoking with adverse effects on their MS and do not feel that their symptoms are made worse by smoking so have not been motivated to think of MS as a trigger to quitting.</p>

Capability (Can people change/act?)	Opportunity (chance to change/act)	Motivation (do people want to change/act?)
	<p>The fact of their own experience trumps the general messaging intent for some people and so we lose the opportunity to persuade them to change their behaviour around smoking</p> <p>Need to determine whether the power of the messaging for some people is worth exposing it (at the risk of letting some others off the hook...when really they too need to address their smoking habit)</p> <p>Suggest it is better to use the general hidden harm approach and not use the lesion specific support?</p>	<p>Motivation to quit smoking for some people is fragile and they seize on any contrary evidence “from the experts” to vindicate their decision to carry on.</p> <p>For some the messaging about lesions is undermined by the fact that their lesions have not progressed for several years... and they know this because of their personal MRI scans...so they can use this to say “this (messaging) doesn’t apply to me”.</p>
<p>Despite being part of a gain framing focus this messaging works partly by shocking those it impacts to look at the arc of their disability – going forward and sometimes backwards. It is scary. It can be a wake up call for them to admit they have been pushing the progression to the back of their mind</p> <p>Again, there is an ethical responsibility to consider the impact of this news on those who have MS and smoke and may be living with little support. Also, to consider what messaging might be appropriate for those with primary progressive MS (as this message explicitly references secondary progressive)</p>	<p>It is important to provide people with MS with a new yardstick for thinking about the impact of smoking on their disease. Focus is <u>not</u> day to day symptoms. It is reframed to talk about disability</p> <p>Thinking about “disability” and the progression of disability over time into the future is inviting people to look forward (and sometimes back) to see that their level of disability has progressed and may well progress in the future (the threat of secondary progressive is part of this for newly diagnosed and those living with RRMS).</p> <p>This is an opportunity to try to impact the effect of smoking on your disability going forward: (gain framing)</p> <p><i>“Quitting improves the chances</i></p>	<p>MS symptoms are highly variable between individuals and for the individual over time. It is easy to say that smoking is not affecting my symptoms day to day (as alcohol or excessive stress or activity may) ... and even if it is doing so, how would I know? MS is a moving target. I can keep smoking (and being in denial).</p>

	<p><i>that you'll be less disabled. And it can also slow down how fast your MS gets worse. One study found that if you quit smoking it slows down how soon your relapsing MS became secondary progressive MS by up to 8 years. So, give your brain a breather....."</i></p> <p><i>"Smoking can make your MS more active"</i></p>	
<h3>3. TWO TRICKY ISSUES</h3>		
	<p>Reject the opportunity to act as it feels like they are being asked to hand over or relinquish control ...an attack on their sense of self and identity.</p>	<p>MS takes away control of the body. It is capricious and cruel. Smoking perversely helps some individuals retain a sense of control. It is something they can choose to continue doing; something that helps them feel less defined by their MS. Something for them.</p> <p>Can create resistance and rebellion in the face of the evidence. <i>"I don't want anyone telling me what I can or cannot do with my body" or "I'll decide when I give up smoking thank you"</i></p> <p>Linking smoking and MS for them threatens their identity as someone who smokes (and by the way has MS)</p>
	<p>Seemingly no opportunity to engage this smoker in the debate or encourage him to change his behaviour...and he believes he is not alone in this</p>	<p>An individual smoker who utterly rejects the propositions because he smokes tobacco to enable him to use marijuana ...totally unmotivated to quit as he believes marijuana helps him daily with his symptoms (and smoking doesn't impact his symptoms negatively so this is a win win) ...even the evidence here on smoking tobacco does not outweigh the benefits for him</p>

## 5. Smoker case studies (examples)

Names have been changed in these examples. The following examples illustrate four types of smoker encountered in the research. The last individual – a smoker who smokes to enable him to use marijuana for his MS was the single example of this typology we interviewed. The first type – the resistant smoker who still enjoys the habit, was also rare. The other two examples broadly represented the rest of the sample in which we encountered a mix of those who were resistant to quitting even though they wanted to and those who were equally keen to quit and who were receptive to messaging.

### 5.1 The resistant smoker who still enjoys the habit

Nora is sixty seven and has smoked roughly thirty to forty a day for many years and started smoking at fourteen. She started when she worked as a Saturday girl in a hairdressing salon because she noticed that those who smoked always got their full break whilst those who didn't might be called back into the salon early. She remembers having driving lessons as a young woman and sitting in the car with her instructor going through the Highway Code as they both smoked. When she passed her test, he took her out for a last time to make sure she could smoke safely whilst driving. Like everyone else interviewed she agrees she wishes she hadn't started smoking but the positives outweigh the negatives for her. She enjoys smoking. She gave up once having had a bet with three men that she could quit for the longest. She went cold turkey and gave up for three years, banking £1500 in savings as she went. She beat the men but started smoking again when her mum died.

She finds smoking helps her to keep her temper when faced with a social situation where the views of others make her want to hit them. She goes outside, has a cigarette and calms down. She knows she can be socially awkward and smoking helps her deal with that. She is a highly intelligent woman with a background in science. She has decided that she probably has another ten years of life left, but if that is shortened to five she will have still had her three score years and ten. She is well aware of the health risks of smoking (in general), though not aware of the specific risks in relation to MS. She was diagnosed in 1999 with RRMS but has had no advancing lesions in the last ten years. At this rate, she has been told by her neurologist whom she quizzed about her lesions and MRI scans, she *"will be in a wheelchair by the time she is 160"*. She rejects the propositions calling the loss framing approach a case of "nanny state". She dislikes this kind of approach and eats butter, cream and full fat milk because she prefers them and as an act of rebellion. Stoptober is a better approach she feels because it sounds more inclusive and encouraging.

*"It wouldn't be a bad thing. To do it on a communal basis. If the cost of the patches and the gum were reduced during October that would be no bad thing too. I like the fact it focuses on everyone around a person with MS and not just that person. Everyone could be involved ...it's not just portraying smoking as the "Big bad Pariah"*

She is not interested in participating in Stoptober herself. She said that if she had definitive evidence that smoking impacted MS, she might consider quitting but is not convinced here as her lesions are not changing in number or size; in general she recovers well after relapses and her

disease is not progressing significantly. She experiences balance and mobility issues due to numbness but manages to continue playing golf and is getting out and about. She listened patiently to the propositions but left the interview unmoved

## 5.2. The resistant smoker who wants to quit but remain unconvinced

Jane aged forty three. Took up smoking when she was sixteen because all her friends smoked plus many more people smoked back then. Smokes around twenty a day. She works full time in consultancy.

Gave up once when pregnant and went back to it three weeks after her daughter was born (eight years ago). Recently tried using a hypnosis App on her phone. She managed to stop for a few months citing the effectiveness of hearing about how the tobacco industry manipulates smokers and make the habit seem glamorous. She slipped back when she was on holiday. Her husband smokes so it is difficult to quit herself and it is sociable for them to smoke together.

She was diagnosed with RRMS 2014. She strongly believes that smoking helps her manage stress, including the stress of having MS. She tries actively to manage stress. She has changed her job and tries to rest more. She knows that stress impacts her MS.

*If I am stressed I feel the energy levels in my body are like a green mist and stress comes and takes the energy out of my body. Physically draining me and then I get more tingling. Smoking is the one thing I turn to immediately, without it I would increase my stress levels"*

She uses smoking as a "timing mechanism". She does tasks then stops for a cigarette at the same points during work and at home. She really wants to stop. She has dreams of being a Paralympian and wonders if this might motivate her. Her daughter and mother really want her to stop too as her daughter is learning about smoking in PSHE.

She is very sceptical about the propositions and the evidence produced.

*"You can't establish how many more relapses you would have had ... I have had a few, not major ones and scans three years apart and no extra lesions"*

*"You would need two people with exactly the same diet, symptoms and all that and one gets to secondary progressive eight years later than the other because they don't smoke"*

*"If there was 100% guarantee that I might feel better, I might accept it"..... "I wish they would just ban smoking and then I would have to stop" "If my mum was reading this (the propositions) she would say give up now... and I'd say I am trying, but it's not my MS making me (stop) ... I don't know what my reason for giving up is (going to be) and maybe that's my problem" ... "Smokers will always find an excuse, that's why they should ban it"*

She remains unpersuaded.

## 5.3. Resistant smoker who is motivated by the propositions to consider quitting

Dina aged forty six. Started smoking aged fifteen because all her friends smoked. Smokes fifteen to twenty a day. Used to run a cleaning company but is now on PIP.

Has given up a few times, through three pregnancies and then gave up once out of the blue going cold turkey for three years (before her diagnosis). Diagnosed with RRMS in 2013. Her disease has progressed since then and she has constant spasms in her hands and feet; migraine, anxiety and depression, mobility issues and her joints "seize up". She is not on a DMT (by choice). She was told on diagnosis that smoking could "*speed the progression of her MS*" and she wants to give up but:

*I tell myself that MS is an excuse not to give up ... "They said I should give up (HCPs) but then said it's probably not a good time to give up now ... And the good time never came I guess"*

She smokes with her mum which is social, after meals and feel that smoking leaves her with some residual sense of control over her life and her own body.

*It's the freedom of what I want to do to my body and put in it when the MS has too much control of my body"*

When asked what messaging might help her she said

*"I don't like being told what to do...it's my rebellious side"*

Significantly though after reading the propositions, Dina sounded much more pensive and shocked. She particularly alighted on the gain-framing proposition about a study saying that

[Quitting improves the chances that you'll be less disabled. And it can also slow down how fast your MS gets worse. One study found that if you quit smoking it slows down how soon your relapsing MS became secondary progressive MS by up to 8 years. So give your brain a breather.....]

*"It's a bit of a reality check" "some food for thought" .... "Because I have had MS for so many years now and they think I had it a long time before that. If I look back to how I was when I was diagnosed and the difference between then and now and then double that time" (i.e. using the eight years going forward) ...*

*"I am going to have a serious talk with myself"*

#### **5.4. Person with MS using marijuana to help pain management**

James started smoking aged sixteen. All his family smoked. He is now forty five and smokes fifteen to twenty cigarettes a day. He gave up once by going cold turkey (and to run a marathon for MS fundraising) but started again a few years ago after a very difficult divorce. In the course of the interview it emerged that he smokes tobacco because he smokes marijuana to help pain management in relation to his MS. He also feels smoking calms him down and helps him manage MS better. MS "*takes away such a lot*" and smoking (in general) is something for him which remains. He was diagnosed with RRMS in 2006 and for a time led a very active life, running long distances. His mobility is now much less, and he manages two walks a day but suffers from chronic fatigue. He is an active member of The MS Society and campaigns for the legalisation of cannabis for people with MS.

He smokes:

*"Eighty percent for the cannabis and twenty per cent for the nicotine."*

In general, he knows that smoking is bad for him because of *"the chemicals and crap it puts into your lungs"* but the benefits outweigh the negatives for him. He has a close friend who is a GP and a good relationship with his neurologist. They both tell him he should stop smoking but neither have linked their reasons to adverse effects on his MS. He feels that the cannabis is very important in helping him manage the pain of MS and in combination with Tysabri (which he has taken for ten years) has helped him to be in the best place he could be now. Importantly he has had no new lesions in that time, so despite the reduction in his mobility, he rejects the propositions about the damage of smoking (related to lesions). Stoptober is a good initiative but his experience is much more about people asking him about cannabis and where they can get it to help manage their MS. He will not stop smoking tobacco because he not willing to stop smoking cannabis.