



**Exploring the potential to use communication to change behaviour  
among people with Relapsing MS**

**Executive summary**

**Headstrong Thinking Limited  
9 February 2018**

## Executive Summary

This document details a project commissioned by the MS Society in 2017 and carried out at the end of that year and the first few months of 2018.

The project aimed to create a working segmentation of people with MS for the purposes of developing communications to change their behaviour with respect to disease modifying therapies (DMTs).

DMTs are not a cure for MS, but they can reduce how many relapses someone has and how serious they are. Currently, 56% of people with MS who could benefit from treatment is taking one. Evidence also suggests the UK lags behind its European counterparts in access to these treatments.

The right information and support has an impact on access to treatment too - when people with MS feel well informed about treatment options, and have access to an MS nurse and a neurologist, access to treatment improves significantly (from 12% to 80%).

In the last 20 years 13 new treatments for relapsing MS have become available on the NHS and research is progressing. However, these advances in treatment mean that deciding which treatment to take, if any, is increasingly complex.

The MS Society therefore commissioned this research to better understand what communications messaging might support people with MS to consider their treatment options and seek advice from their neurologist or nurse.

The project involved desk research, four stakeholder interviews (internal MS Society staff members) and three healthcare professional interviews (two with neurologists and one with a Health Sciences professor), the issuing of an open invitation to contribute to the MS community, a workshop with MS Society personnel, proposition development and two phases of original research, both qualitative. Phase one of the research was conducted online, among eleven people with MS. Phase two involved online research with nine people affected by MS and thirteen individual telephone depth interviews with people with MS- seven existing participants from phase one and six new participants recruited specifically for phase two.

In advance of the research, a hypothetical segmentation was generated, which differentiated between people along two axes:

- Whether people viewed their MS as extrinsic (i.e. something that happened to them) or intrinsic (i.e. as something that, while challenging, was a part of them)
- The way in which people preferred to interact with healthcare professionals, specifically if they tended to (or, on occasion, were forced to) rely on the healthcare professional to make decisions for them or whether they wanted to be an active participant in decisions about their own care.

These axes generated four segments, which were given the names “Warriors”, “Followers”, “Harmonisers” and “Fatalists”.

Using these segments as a framework for generating ideas, five propositions (headline messages) were developed and explored in the research. These propositions were informed by principles from behavioural science such as social norming, loss and gain-framing, optimism bias and priming.

The five propositions were: “Social Norming”, “Expert Endorsement”, “Loss Framing”, “Gain Framing” and “Think Again”.

Due to the iterative nature of the research, there was the opportunity to rewrite propositions between phases one and two.

Main findings:

- There is real need for this initiative. While some people with MS reported being well supported by their neurologist and/or MS nurse to make informed decisions about DMTs, others were not. Knowledge about the current availability of DMTs was suboptimal for many and the world of DMTs can be complex and confusing.
- Stakeholders involved in the research felt that access to DMTs, adherence to treatment and information and support needs were influenced by a variety of factors, including:
  - A lack of acceptance of a diagnosis of MS, can mean being able to take in and act on, or even accept, advice about DMTs is extremely challenging, and may lead to a treatment delay
  - People not being informed about newer drugs, which might suit them better, which may mean they are driven to lapse in their treatment by side effects
  - A lack of support and adequate framing of up-front expectations about short term side effects, so that people may give up DMTs prematurely and/or not replace with another option
  - Systemic factors, including a lack of time for quality treatment conversations, can mean insufficient advice and understanding of individual considerations
  - An MS specialists approach to treatment conversations, including how directive they are, how much they know about newer drugs, how much they will take a “wait and see” approach (possibly responding to economic pressures over the cost of drugs) and a historical emphasis in training on developing skill in diagnosis, rather than in discussing treatment
  - The pattern of initial diagnosis followed by brief annual patient reviews can frustrate effective dialogue between patient and clinician.
- The project largely validated the hypothetical segmentation, although with some nuance and adaptation, specifically the axis describing how people interact with healthcare professionals was amended to reflect the quality and depth of the relationship between patient and clinician, rather than how patients prefer to interact.

- Following the work of Professor Susan Michie and colleagues at UCL, the authors argue that, for people with MS to change their behaviour in respect of DMTs, three factors all need to be in place: capability, opportunity and motivation. Capability includes factors like having personal confidence and assertiveness in the face of a neurologist's possible lack of engagement and "power"; opportunity includes factors like having an annual neurologist appointment; motivation includes factors like associating taking DMTs with psychological benefits, such as feeling a little more in control of MS.
- Against this backdrop, elements of all five propositions were positively received and prompted reassessment and, in some cases, immediate action (for example three research participants reported scheduling appointments with their MS team as a result of taking part in the research).
- Possibly the single most motivating piece of information was that, even if people are not having relapses, MS can be affecting their brains, without them knowing it. This disrupted people's current means of gauging the progression of their MS (which is currently linked to the frequency and severity of relapses).
- Following the qualitative phase, it is recommended that two propositions, "Gain Framing" and "Loss Framing" go forward to quantitative research, both of which leverage this new piece of learning.
- Quantitative research is recommended, since qualitative research, while providing deep insight and understanding of why people respond as they do, can be skewed by small sample sizes and respondent bias.
- Recommendations are also made for using no cost and low cost channels to further disseminate the strongest concepts emerging from the quantitative research. These include search engine optimisation, social media and email. Attention is also given to reaching lower socioeconomic groups and younger women, for example via partnerships with central and local government and the creation of digital assets to be downloaded by healthcare professionals.
- Recommendations are made for further projects, including deeper engagement with healthcare professionals and expanding the 'winning' concept(s) into physical activity and smoking cessation.
- People with MS contributed to this work throughout. It is the MS Society's intent to share the findings with people who took part in the project,
- All data, screeners, questionnaires, propositions and data generated by this project are now the property of the MS Society.