

Bridging the Support Gap:

Translating Patient Journey Insights into Practice through a Comprehensive MS Patient Support Programme (PSP)

Claudine Dawkes, Anna Meadows, Helen Bennis, Will Bench, Laura McBride and Helena Morris

Background

- To inform the development of a PSP for people with multiple sclerosis (MS), a programme of qualitative research was conducted.
- One-to-one interviews were carried out to gain an in-depth understanding of the MS patient journey and to identify key areas of unmet need where a PSP could have a positive impact on patients' experience

Methods

- 45–60 minute qualitative interviews were conducted Dec 2024–Jan 2025 in UK and Ireland with a purposively recruited sample of n= 25 people living with MS (see Fig. 1).
- Data was analysed thematically using a COM-B framework (see Fig. 2).

Final sample

Figure 1. Final Sample

		UK (n=15)	Ireland (n=10)
Treatment	Naïve	2	1
	Infusion therapy	8	5
	Subcutaneous injection	2	2
	Oral therapy	1	2
Clinical subtype	Clinically isolated syndrome	-	1
	Relapsing remitting MS	12	9
	Secondary progressive MS	3	-

COM-B

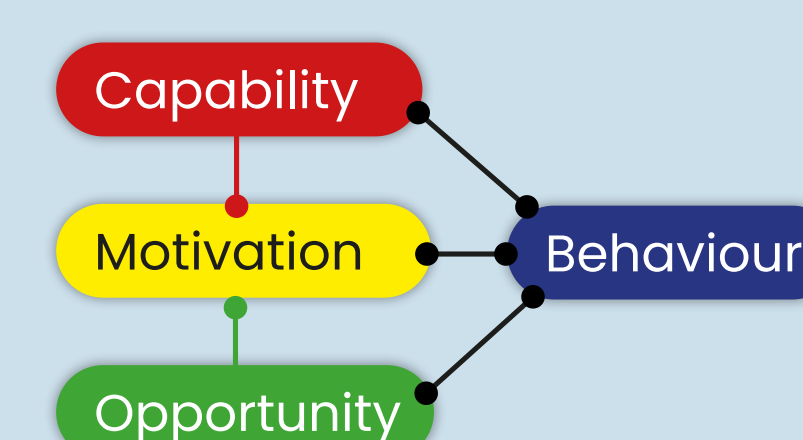


Figure 2.

Support at key touchpoints is not always apparent or adequate

Who? Neurologists, MS Specialists

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What? Diagnosis and initial advice given in one consultation. Patients in emotionally 'hot state' and unable to fully process diagnosis or information regarding treatment options

How can the PSP address this?

Acknowledging emotions and providing simple, patient-friendly information that reassures and manages expectations

Recommendations for the PSP:

- Post diagnosis nurse support
- Direction to peer testimonials
- Provision of materials guiding next steps / treatment options

Motivation

Diagnosis

Months or even years can pass

Who? Neurologists, MS nurses

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What? Most patients look to Neurologist to make treatment choice as do not feel fully equipped for shared decision making. Minority make active choice but not always accepted by Neurologist. Once decision is made, patients feel more positive about journey ahead.

How can the PSP address this? Facilitate discussion between HCPs and patient – reduce barriers to communication

Recommendations for the PSP:

- Suggest questions to raise with the HCP
- Model acceptable behaviour for patients
- Their right to ask and question

Capability

Motivation

Opportunity

Treatment

A few weeks or months

Who? Intravenous (IV) nurses

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What? First infusion experience is more positive than patients expect. Post infusion, patients report enjoying the attention of IV nurses during monitoring. Initial anxiety eased by positive experience of IV set-up and care. Patients feel suitably supported and are receptive to communication

How can the PSP address this?

Induce positive feelings, facilitate focus by patient on their condition

Recommendations for the PSP:

- Positive framing of infusion as a time for patient to focus on themselves and connect with health
- Encourage patients to raise unanswered questions – provide FAQs

Motivation

Opportunity

First infusion and monitoring

A few weeks or months

Who? Intravenous (IV) nurses

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What? Completing infusions both mentally and physically depleting – experience of initial infusion influences perceptions of subsequent infusions

Patients easily adapt and accept IV practicalities, but emotional anxiety of long-term treatment can persist

How can the PSP address this?

Remind of previous positive experience, build capability in relation to infusions

Recommendations for the PSP:

- Assist planning of repeatable infusion routine
- Prompts / reminders of previous positive experience

Capability

Motivation

Subsequent infusions

6 months

Predagnosis

Pretreatment decision

Before the first infusion

Post-treatment/follow-ups

General practitioners, neurologists, radiographers & technicians

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What? Variations in how MS manifests, inconsistency in access to health resources and lack of familiarity with symptoms from some PSPs can lead to delayed diagnosis and stress and uncertainty for patients

This 'diagnostic odyssey' can mean that patients are physically and mentally depleted from the very start of the journey

How can the PSP address this?

Needs to be considerate of possible patient low mood and motivation from outset

Motivation

MS Nurses, Family and Friends

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What? HCPs hesitant to dictate most suitable treatment and encourage patient to choose. Patients do not feel fully equipped to make complex decision – lack capability and motivation.

How can the PSP address this?

Guide treatment decisions, encourage confidence in ability to choose

Recommendations for the PSP:

- Build on current decision tools; align with personalised choice criteria
- Develop road maps of each treatment, demonstrating expectations, process, experience and outcomes
- Provide chatbot / helpline to assist in tailoring choice

Capability

Motivation

Opportunity

MS Nurses, Family and Friends

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What? A long time can pass between treatment selection and first infusion; patients lack understanding of what to expect. Anticipation anxiety builds, heightened by lack of HCP engagement during this period

How can the PSP address this?

Induce positive feelings, manage expectations of experience to reduce anxiety. Assist with practicalities

Recommendations for the PSP:

- Explain what to expect before, during, and after IV (e.g. guides, virtual tours)
- Emphasise supportive environment of the IV centre
- Provide tools to help manage visit planning and logistics

Motivation

Opportunity

MS Nurses, MS Specialists

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What? Management and support wanes upon leaving IV centre. No reference point as to how they should feel or what they should be working towards. Little opportunity to connect with HCPs or peers can contribute to low mood and anxiety

How can the PSP address this?

Reinforce association between treatment, positive progress and feeling good, reduce barriers to connection with others

Recommendations for the PSP:

- Reassurance that progress is being made
- Provide proactive HCP check-ins
- Create opportunities for patients to connect

Motivation

Opportunity

KEY FINDING: The time between touchpoints is where support is most needed but currently lacking

Conclusions:

- There are distinct touchpoints across the MS journey: diagnosis, treatment decision, infusion, monitoring, follow-ups and subsequent infusions (if treated by IV)
- Whilst some elements of support already exist at these points, knowledge of, and access to, that support is inconsistent
- More importantly, the journey is also characterised by long periods between each touchpoint where patients report the greatest need for emotional, practical, or informational support, but find the current provision to be lacking and can feel they are left to cope alone
- An opportunity exists to provide a more accessible and consistent programme of support for those living with MS

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Neuraxpharm commissioned a comprehensive patient study to inform a strategy to support the patient through their MS journey.

Research was required to gain an in-depth understanding of MS patients' journey, and critically, patient unmet needs in order to develop a patient support programme designed to positively impact patients' experience.

Research objectives:

- Mapping the MS patient journey, uncovering the full range of patient experiences
- Identifying touch points, HCP-patient interactions, pain points/unmet needs from diagnosis through to treatment
- Assessing commonalities and differences for IV, SubCut, treatment-naïve patients, and across markets

Sample and Method:

- Mix of patients diagnosed with Relapse Remitting MS, Secondary Progressive MS, or suspected MS /clinically isolated syndrome

	Engagement	UK	Ireland
IV Naïve	45-min TDI	2	1
IV Experienced	60-min TDI	13	9