Research Square

Preprints are preliminary reports that have not undergone peer review.
They should not be considered conclusive, used to inform clinical practice,
or referenced by the media as validated information.

Exploring perceptions and attitudes towards Multiple Sclerosis (MS) risk and prevention: A qualitative study

Isabelle Symes
Wolfson Institute of Population Health, Queen Mary University of London
Lucy Wright
Wolfson Institute of Population Health, Queen Mary University of London
Mark Leach
Anisha Gangotra
Marion McAllister
Cardiff University
Gavin Giovannoni
Queen Mary University of London
Will Brown
University of Cambridge
Ruth Dobson
Wolfson Institute of Population Health, Queen Mary University of London
Marie Falahee
University of Birmingham
Alison Thomson
a.thomson@qmul.ac.uk

Wolfson Institute of Population Health, Queen Mary University of London

Research Article

Keywords: multiple sclerosis, risk communication, prevention, qualitative, patient and public involvement

Posted Date: November 23rd, 2026

DOI: https://doi.org/10.21203/rs.3.rs-11653102/v1

License: This work is licensed under a Creative Commons Attribution 4.0 International License.
Read Full License

Additional Declarations: No competing interests reported.

Abstract

Background

Multiple sclerosis (MS) is a leading cause of disability in young adults, with prevention identified as a research priority. Given the complexity of risk communication, understanding the perspectives of people with MS (pwMS) and their first-degree relatives (FDRs) is central to developing ethical communication strategies and prevention study design.

Methods

This qualitative study used semi-structured interviews and focus groups to explore pwMS and FDRs' perceptions of risk and prevention. We recruited 20 pwMS and 20 FDRs through Patient and Public Involvement (PPI) networks. We analysed transcripts using reflexive thematic analysis.

Results

Participants described managing uncertainty and limited knowledge around risk and prevention. Strategies ranged from avoiding information to seeking certainty through researching MS. Many reported limited accessible information and wanted digestible, signposted resources at relevant stages. Both groups reflected on responsibility for risk factors, prompting self-blame and questioning level of control. Family communication about risk was constrained by efforts to protect relationships and avoid distress, with different cultural contexts and family dynamics shaping conversations. Although both groups were hopeful for prevention, they expressed concerns about invasive measures and pressures on FDRs to participate.

Conclusion

Findings highlight a need for evidence-based information from trusted providers to support better understanding and conversations about MS risk and prevention, and for ethical recruitment procedures for prevention studies. Resources should be tailored to enhance accessibility, inclusivity, and differing informational needs.

Background

Multiple sclerosis (MS), a chronic neuroinflammatory and neurodegenerative condition, is a leading cause of neurological disability in young adults[1]. It is estimated that within the United Kingdom (UK) there are over 150,000 people with MS, with 7,100 new diagnoses each year[2]. Common symptoms include, but are not limited to, changes to sensation and weakness in the body, fatigue, vision problems, memory impairment, and impaired balance, with symptoms greatly impacting quality of life[3].

Current evidence indicates the development of MS is associated with complex interactions between genetics, demographics, and the environment. Smoking, vitamin D deficiency, obesity during adolescence, and infectious mononucleosis or glandular fever (caused by Epstein-Barr virus (EBV)), are among the most established potentially modifiable risk factors of MS[4]. Established non-modifiable risk factors include polygenic risk score, human leukocyte antigen (HLA), family history, biological sex (females), and latitude at birth[4].

Currently, there is no cure for MS. Significant progress has been made in disease-modifying treatments, with current MS research predominantly focused on stopping the disease process[5]. Limited attention has been given to primary and secondary prevention initiatives[5], despite prevention identified as a priority by the James Lind Alliance's Priority Setting Partnership for MS[6]. National and international initiatives are underway to address this, with key next steps for prevention studies identified including defining the MS prodrome, prioritisation of interventions, and public engagement to facilitate ethical recruitment to prevention studies[4]. Primary prevention focuses on actions taken to avoid disease onset in an unaffected population, whereas secondary prevention involves early detection[4]. The possibility of intervening before the clinical onset of autoimmune disease has recently progressed, with teplizumab approved to delay progression of presymptomatic disease to clinical onset of type 1 diabetes[7]. However, this introduces complex decision-making, and efforts to understand individuals' and caregivers' perspectives on disease risk, screening, and preventive treatment are key to acceptability[8].

As MS prevention research progresses, understanding of the perceptions of those affected is becoming increasingly important due to the complexity of risk communication, including how risk information is received, understood, and responded to. However, there is a gap in understanding of the perspectives of people with MS (pwMS) and at-risk populations such as first-degree relatives (FDRs) towards MS risk and prevention. Across other disease contexts, especially polygenic conditions, reported challenges associated with genetic risk disclosure include the ethics of using genetic susceptibility testing, informed consent, health literacy and cognitive biases, and the potential psychological and behavioural impact of results[9]. In rheumatoid arthritis (RA), a multifactorial autoimmune disease with genetic and environmental factors[10], these challenges are becoming increasingly relevant, with prevention studies advancing[11], and the most recent trial reaching primary endpoint (The APPIPRA study)[12].

Concurrently, patients' and relatives' perspectives regarding risk and prevention have been explored in RA to understand potential barriers to risk communication[13–16]. Key findings highlighted the commonality of selective communication of risk information, feelings of guilt and responsibility when considering disclosure decisions, a lack of knowledge about the causes of RA, misperceptions about risk information, and concerns about pharmacologic interventions and their potential benefits[13]. Patients were concerned about the potential psychological harm of their FDRs being labelled as 'high risk' and social consequences such as discrimination[17]. However, the likelihood of people with RA communicating RA risk information with their FDRs was often motivated by a hope to empower their FDRs, enabling informed decisions to potentially reduce their RA risk[17]. Barriers to recruitment of at-

risk individuals to RA studies include potential participants' perceptions about the potential for benefit, negative views about pharmaceutical intervention, and perceived burden of study participation[18].

These insights are key to shaping ethical and effective risk communication and preventive approaches; however, these topics have not yet been explored in MS. The Genes and Environment in Multiple Sclerosis (GEMS) nationwide prospective study found that FDRs of pwMS who were originally undecided or not interested in participating in future primary prevention trials showed increased willingness when informed of their elevated genetic risk[19]. Although this demonstrates that risk information can influence participation in prevention research, little is known about the underlying beliefs, motivations, and concerns underpinning these perspectives.

This study aimed to address the gap in understanding of the perspectives and attitudes towards MS risk and prevention among pwMS and FDRs. We sought to understand (1) how pwMS and FDRs perceive risk factors and attitudes towards prevention strategies, (2) the factors that shape their understanding of risk and prevention, (3) how these groups feel about family communication about MS risk, and (4) communication and support needs and preferences when discussing MS risk and prevention.

Methods

Design

This qualitative study used semi-structured 1:1 interviews and focus groups to explore the perceptions and attitudes of pwMS and FDRs. Patient and Public Involvement (PPI) shaped every stage of the research process. Ethical approval was obtained from Queen Mary University of London Ethics Committee (QME25.0942), and the research was carried out in accordance with the guidelines and regulations of this committee. The Standards for Reporting Qualitative Research Checklist[20] was used for qualitative research reporting (see Supporting Information 1).

Participants

Eligible participants were based in the UK and were either:

1. People living with MS aged 18+, or
2. FDRs of someone living with MS who do not have the condition themselves, aged 18+.

PwMS and FDRs did not need to have a relative enrolled in the study to participate. Participants were recruited through existing networks at QMUL, including MS Peer Research Network, the ADAMS Study network, and the Centre for Preventive Neurology (CPN) MS Newsletter. Social media campaigns were posted across the CPN social media accounts (including Instagram, TikTok, LinkedIn) and shared via the MS Society 'Be in a study' webpage and two MS Society webinars. Recruitment took place between

August 2025 and January 2026. The majority of pwMS were recruited through existing networks and the CPN MS Newsletter.

FDRs were recruited predominantly through word-of-mouth from family members with MS. Because FDR recruitment was prolonged, we additionally recruited via Trusted (https://www.trusted.org.uk/) and Professor Gavin Giovannoni's MS-Selfie Newsletter (https://msselfie.co.uk/), which helped us reach the recruitment target. Trusted received favourable ethics opinion from London-Bromley REC (23/LO/0144).

Participants expressed interest by emailing a researcher (IS), were contacted via email or phone, and invited to an interview/focus group (in-person or online), according to their preference and availability. Participants were purposively recruited to include perspectives from underrepresented communities.

Data collection

PwMS and FDRs were interviewed separately, as previous PPI work suggested that experiences of pwMS and FDRs' concerns surrounding the risk of developing MS would require different interviewing approaches. Two separate topic guides (pwMS, FDRs) were developed with input from the PPI advisors (see Supporting Information 2).

Before the interview, participants completed the consent form, participant information sheet, and background questionnaire, either via email or verbally. One researcher (IS) conducted the interviews and focus groups via Zoom, Microsoft Teams, and in-person at QMUL. The semi-structured interviews lasted up to one hour, and the focus groups lasted up to two hours. Interviews and focus groups were audio-recorded and professionally transcribed verbatim. Transcripts were anonymised and de-identified during transcription. Data collection ceased after 20 pwMS and 20 FDRs had participated in interviews or focus groups.

Data analysis

Analysis was conducted in parallel with data collection. Transcripts were analysed using reflexive thematic analysis[21], adopting an inductive approach with essentialist epistemology and experiential orientation[22]. The transcripts were coded in NVivo 14. One researcher (IS) coded all the transcripts, and 22/33 transcripts (66.67%) were double coded by a second researcher (LW). The team explored similarities and differences in coding through discussion. PPI advisors reviewed the initial codes as a form of member checking and highlighted ideas that needed further exploration. The codes were developed into initial themes, which received feedback from the PPI advisors, research team, and the UK MS Society Prevention Taskforce.

Reflexivity

Throughout data collection and analysis, we engaged in ongoing reflexive practice through reflexive journalling and discussions with the research team. Our differing experiential and professional backgrounds informed the analytic process, bringing together lived experience of MS, qualitative research, and clinical insight. As the data collection and analysis progressed, interpretations informed subsequent follow-up questions within interviews.

Patient and public involvement

PPI input at the study design stage through the UK MS Prevention Taskforce shaped prioritisation of the research question, the framing and ethical sensitivity of the research, and the development of the research funding application. Two PPI advisors (one pwMS (ML) and one FDR (AG)) contributed throughout the study to ensure it accurately reflected lived experience. An initial meeting with pwMS and their FDRs identified via the MS Society Research Network informed the development of the research questions and study methodology. AG and ML participated in regular meetings addressing ethics, study design, recruitment strategies and materials, analysis, interpretation of findings, and dissemination planning. They directly informed revisions to the topic guides, recruitment materials, and consent processes, ensuring the materials were accessible, respectful, and culturally informed. They contributed to reflexive thematic analysis by reviewing initial codes and theme development.

Results

In total, 11 pwMS participated in semi-structured interviews and nine pwMS participated across two focus groups. All 20 FDRs participated in semi-structured 1:1 interviews due to individual participant preferences and staggered availability. Table 1 displays participant characteristics.

Table 1
Participant Characteristics (n = 40)

Characteristic		Number of Participants
Gender	Female	26
	Male	14
Age	18–30	12
	31–40	6
	41–50	4
	51–60	12
	61–70	3
	71–80	3
Self-Reported Ethnicity	Arab	1
	Asian/Asian British-Indian	3
	Asian/Asian British-Pakistani	6
	Black Caribbean	2
	Black Caribbean/Black British	1
	British Sri Lankan	1
	Moroccan/White British	1
	Persian	1
	White/Black African	1
	White British	20
	White British/White Greek Cypriot	1
	White Irish	1
	White Irish/Italian	1
Highest Education Level	A level or equivalent	5
	Degree of equivalent	18
	Postgraduate qualification	15
	Vocational qualification	2

In pwMS, the median number of years since MS diagnosis was 11 years [range = 2–28 years]. In FDRs, the most frequent age range was 18–30. When asked how likely it is that they will develop MS, 80%

(16/20) of FDRs answered ‘neither unlikely nor likely’, 15% (3/20) answered ‘unlikely’, and 5% (1/20) answered ‘likely’ on a five-point Likert scale from very unlikely to very likely.

In total, 10 FDRs had a sibling with MS, eight FDRs had a child with MS, and seven had a parent with MS. Additionally, several pwMS and FDRs within the sample were related, including two pairs of siblings and three parent-child groups.

Reflexive thematic analysis

Four overarching themes were developed from the data, displayed in Table 2.

Table 2
Overview of results

Theme	Sub-themes
Managing uncertainty	• PwMS and FDRs have different starting points but similar struggles • Navigating feeling ‘at risk’ • Rationalisation of related risk factors and avoidance of information • Establishing certainty and confidence through knowledge empowerment
Allocating responsibility, control, and blame	• Self-blame and questioning control over MS • PwMS taking on the role of educator • Risk and reward decisions • Systemic factors beyond individual control
Protecting relationships and emotional balance	• Avoidance of distress and discomfort • Focusing on the present over the future • Cultural stigma and misconceptions • Complex family dynamics
Enabling informed choice and accessibility to information	• Quiet hopefulness for prevention and unanswered questions • PwMS shape information flow and FDR engagement • Need information starting point and increased visibility • Individual information needs

Managing uncertainty

Participants described feeling uncertain of the factors associated with the development of MS and their own risk, which shaped how they interacted with information. This is explored in four sub-themes.

PwMS and FDRs have different starting points but similar struggles

Although pwMS often had more exposure to information and networks about MS, both pwMS and FDRs expressed confusion about risk factors. Participants described experiencing uncertainty over what the terms risk and prevention actually entail in the context of MS. For some, risk felt like an abstract concept, with the probabilistic nature of risk complex:

"I wouldn't say risk. I would probably say, "What's the likelihood?" I know it's the same thing, but it's not. Risk tells you, you've got an option. For me, that's how my brain works with it. And really, there is no option. It's the luck of the draw. If you get it, you get it. If you don't, you don't" (pwMS)

The risk of developing MS, the management of MS, and the prevention of MS worsening were often spoken about interchangeably. Uncertainty around these terms led several participants to list general factors such as lifestyle and stress as influential or use infectious terminology to form analogies. For many participants, risk factors were perceived as having little influence on the development of MS:

"People live normal lives and they just contract it normally just like any other illness, do you know what I mean?" (FDR)

Navigating feeling 'at risk'

Many FDRs felt background anxiety surrounding feeling at risk of developing MS. For some, this feeling fluctuated, with health behaviours used as a coping mechanism to regain control:

"Some days I think 20% to 30%, but then sometimes when I think about it in depth then maybe I go to 50%, 60% chance. […] When I'm exercising and eating healthy then I'm like, I'm good, so I'm good to go and nothing is going to happen. I think that's when […] I'm less scared of it" (FDR)

Others felt their anxiety around the development of MS would subside when they reach particular milestones, such as age:

"It's like when I do a certain life stage and I get over it I'm like, oh okay, I'm still fine, I'm still healthy. So my mum had me I think when she was 33 or 32 and I'm going to be 32 next year, so I might have a different feeling once I'm past the age that she got it." (FDR)

Conversely, many pwMS did not associate their FDRs with being at risk of MS, especially parents and siblings. FDRs were unsure about whether they would want to know more about their risk of MS, particularly with the absence of clear actionable steps to reduce risk.

Rationalisation of related risk factors and avoidance of information

In an attempt to distance themselves from the risk of developing MS, FDRs would often seek reassurance from identifying risk factors that they felt did not apply to them and avoided information as a coping mechanism to manage their anxiety:

"I think it's around not wanting to find stuff out that makes me overthink or panic and think, "Oh god, this is what can happen to me and there's nothing I can do, and what's that going to mean for my family?" That kind of thing. So, I think also that kind of ignorance is bliss thing" (FDR)

Many FDRs acknowledged this approach may not be sustainable, however, breaking that pattern was challenging, especially after extended periods of avoidance:

"I think part of that is trying to stick my head in the sand and pretend that not knowing is better, but I also know that doesn't help necessarily, because it just makes the anxiety grow." (FDR)

Some FDRs had also experienced health scares which increased their anxiety about MS, with one participant reassurance-seeking through medical tests.

Establishing certainty and confidence through knowledge empowerment

Researching and gaining insight into the latest theories around the development of MS was empowering for some participants, particularly pwMS. Most of this research was self-directed, with very little information provided at initial diagnosis. Often this was driven by the motivation to understand why they developed MS:

"I did ask my consultant how and why I might have this and I think he was like, "It's just kind of one of those things really". And I kind of went away and did my own research, and again came to the same conclusion" (pwMS)

This lowered feelings of anxiety around genetics for some pwMS and allowed them to understand risk as multifactorial:

"I am concerned about my children, although reassured when I do read that it's so complicated that the risk is diminished." (pwMS)

Fewer FDRs researched risk factors; however, several expressed a new motivation to understand more in order to lower their anxiety:

"I think I'm definitely going to do some more research on the risk factors. But I think it will calm some of my anxieties, understanding. Because I think when you don't know anything, your brain can go from zero to

1000 really quickly, and it can make up a lot." (FDR)

Allocating responsibility, control, and blame

When discussing risk factors and prevention, level of control and responsibility surrounding MS risk were considered and explored in four sub-themes.

Self-blame and questioning control over MS

Reflecting on potential modifiable risk factors triggered feelings of self-blame in pwMS, with some considering the impact of health behaviours on later diagnosis:

"When I was diagnosed, my vitamin D was really low, and I thought, "How simple it would have been, just to have been taking vitamin D and maybe there is a chance that it might not have happened." I mean, it's all hindsight now." (pwMS)

The term risk elicited negative connotations for participants, perceived as deflecting blame onto the pwMS:

"I do understand how it's phrased, and I get that, but I think there's sometimes a risk of making it seem more that it's your fault than it actually is. And the whole thing about ways to prevent, it kind of gets you into the cycle of 'could have done this, should have done this'." (pwMS)

For some, this blame fell on parents of pwMS, with participants struggling to identify why MS develops and how controllable it is. This caused tensions within families, with FDRs seeking reassurance from pwMS about the cause of their diagnosis, and others holding animosity towards family whom they blamed:

"There was a little bit of sensitivity about kind of my mum asked did I cause this because of the anxiety that happened in my childhood? […] My sister blamed my mum for a very long time and there was a lot of anger towards my mum." (pwMS)

PwMS taking on the role of an educator

PwMS often described feeling a responsible for sharing information and current MS research with their family members. Some enjoyed the opportunity to speak about MS and educate others. However, this role could sometimes be a burden, especially when mediating conversations and correcting stigma and misinformation:

"I try and educate people, "Actually it's the leading cause of disability in young adults". Yes. If I really can't be bothered I'll just ignore them [laughs]. Depends what kind of mood I'm in." (pwMS)

Confidence in understanding shaped the likelihood of information sharing, with some pwMS feeling uncertain about MS risk information, so choosing to avoid discussing it. For most FDRs, this is the only

source of information they access about MS, with pwMS tailoring information to their FDRs and prompting them to learn more:

"I think she also knows kind of the way I take in information, so she's able to talk to me in a way where she knows that I will be receptive to what she is talking about. […] I don't usually go out hunting for it." (FDR)

Risk and reward decisions

Many spoke about confusion over conflicting information shared around MS risk factors and prevention. This led parents to consider which health behaviour or guidelines to implement:

"You can read all these things, and they might have a little bit of evidence base for MS, but they don't have evidence base for the rest of your life […]. And you could definitely argue with that, well the risk factor of not wearing SPF is a lot greater, I'm sure, than the risk of MS. And I think it's really difficult to weigh everything up" (pwMS)

For some, the genetic risk of MS influenced their decision to have children, with the chance of their children developing MS in the future feeling too uncertain:

"She's [daughter] made the conscious decision not to have children. And my son is the same; he's made a conscious decision not to have children. Even though it's not this direct link like that, they've both made that decision. And again, that was probably to minimise risk of passing it on to children further down the line." (FDR)

Systematic factors beyond individual control

When considering responsibility and control over MS, often participants spoke about systemic factors that were out of their control. This included delays to diagnosis due to stigma and misconceptions from healthcare professionals:

"And one of them said, "Oh no, he can't be, he's Asian." I went, "Alright, okay." The consultant, the neurologist, heard them, and he stormed over, and he took them aside[…]. He had the test results back that it was MS. They were under the myth that Asian people don't get MS." (pwMS)

Complex diagnosis journeys caused questions surrounding how early detection would be feasible given these barriers to support and care:

"If you shove and push and scream and pay, you are still looking at nearly ten years. You don't have ten years. You are so ill by that stage, the damage is already done." (pwMS)

Differences in care and treatment across locations in the UK were highlighted as a key systemic barrier to prevention. Furthermore, health guidelines differ globally, with some family members receiving different care recommendations:

“My sister lives in Australia, and she’s had a baby recently. And she told me that she was talking with the baby’s doctor and asking about family history and stuff, and she mentioned that I’ve got MS, and apparently their doctor over there said ‘okay, well let’s start right now on the vitamin D droplets for the baby’. I was like, ‘oh wow, that’s really proactive’.” (pwMS)

Protecting relationships and emotional balance

Family communication and collective emotional context shaped when and if participants communicated about MS, with conversations around MS risk and prevention often limited due to balancing these dynamics. This is explored in four sub-themes.

Avoidance of distress and discomfort

Many pwMS and FDRs were apprehensive to approach conversations around MS risk, concerned about potential unsettling reactions from their loved ones:

“I could see that, me talking about it, you could see the fear in him, maybe for himself, for his children, but definitely for me as well.” (pwMS)

In an attempt to control this distress, some would avoid conversations about MS risk and MS in general:

“I know my parents are already worried about it, so I don’t want to add on to that by saying I’m also worried about it.” (FDR)

Conversations were particularly challenging near the initial diagnosis of MS, with conversations more likely to occur after loved ones had time to process the diagnosis. Navigating different reactions placed a burden on pwMS, with little capacity left to discuss topics such as risk:

“I’ve a mum who won’t really discuss it at all, I have a sister who cries every time she talks about it, I have another sister who she’s trying to be supportive, but I can tell she’s very uncomfortable talking about it.” (pwMS)

Focusing on the present over the future

Conversations specifically surrounding MS risk within this sample was limited, with most FDRs focusing on pwMS’s current health, including new symptoms they were experiencing, relapses, and treatment. Many of their conversations centred around providing support for pwMS, and several FDRs prioritised conversations about support over risk conversations:

“I needed to work out how to support her rather than worrying about myself.” (FDR)

Sometimes, this was due to concern around redirecting conversations to shift the focus to themselves:

“Maybe on one hand, I thought I don’t want to make it about myself. Which I know is silly, but maybe there was a bit of that.” (FDR)

Cultural stigma and misconceptions

Cultural misconceptions about MS and disability, for example, attribution of the development of MS to sin or karma, presented challenges for participants speaking openly with some of their family members:

“There was an aunt that they had who, being in a West Indian environment, they respond differently to illness. It can either be on a religious level, where someone’s done something to you and it’s created this, or you’re a sinful person, and this is the outcome of it, it’s God’s retribution.” (pwMS)

MS became a subject they felt unable to discuss, with additional barriers to communication such as language further complicating understanding of MS. Due to experiences of stigma relating to MS, participants engaged in limited conversations beyond their immediate family about MS, including selective disclosure of their MS diagnosis:

“we don’t really talk about it in terms of my wider family, let’s say, my grandparents’ house or my first cousins. […] not everyone knows I have the condition, so it’s still a taboo subject, it’s not really widely spoken in family” (pwMS)

Emotional and relational distancing from family members due to misconceptions about MS weakened family ties and contributed to strained relationships:

“Then it led to isolation. To the extent that they [family] wouldn't contact you, they wouldn't invite you to events because you'd said no to one or two events during that period. Again, being very family-oriented, that hurts.” (FDR)

Complex family dynamics

One of the main barriers to conversations around risk and prevention was complex dynamics within family units. Relationships between family members were extremely varied across the participants, with some experiencing very open dynamics, and others more conflict-prone:

“I think I have a bit of a different relationship with my mum than my sister does, so I think I get a lot of stuff from my mum firsthand, and I don’t know how much my mum discusses that kind of stuff with my sister. But I don’t really discuss it with her that much.” (FDR)

A lack of openness and trust among family members at times led to selective disclosure, especially when individuals felt shame about MS or believed they could not comfortably open up about it:

“From my side, I have two brothers, one of whom also has MS. But […] I had no idea he had it too. He kept everything to himself. Only when I shared my condition, "I've got it too." Well, why didn't you share it with us? He never does, and that's such a shame.” (pwMS)

Some participants felt they needed to feel a sense of closeness to family members in order to share their experiences with MS. For some FDRs, the complexity of their family relationships made it difficult to navigate conversations around MS where communication was already strained:

"I get that he's got a lot more things to deal with than we do, but also part of me is, like, well, I also know his personality […] I think I have had a couple of conversations with my mum before about it, and it's like we don't really know how much is him struggling because of MS." (FDR)

Enabling informed choice and accessibility to information

Communicating future prevention initiatives and information about risk factors was contingent on providing accessible, visible resources and sensitivity to family dynamics. This is developed through four sub-themes.

Quiet hopefulness for prevention and unanswered questions

Many participants expressed uncertainty about how prevention would be achievable given the cause of MS is still unclear:

"How can you prevent something when you don't know where it comes from, what causes it?" (pwMS)

Although pwMS and FDRs were generally willing to take part in or share information about potential future prevention initiatives, FDRs questioned whether they would want to learn more about their own MS risk and how that might influence their willingness to participate. Many participants emphasised that their participation would depend on what the study involved, shaped by whether the study felt manageable, meaningful, and aligned with their personal circumstances. Several participants had concerns about potentially invasive or burdensome measures, with some pwMS feeling responsibility for any discomfort their FDRs might experience if they chose to take part:

"I wouldn't want them to have anything painful done, if it was just on my behalf, type of thing, and I would feel responsible." (pwMS)

When considering participation in future prevention initiatives, pwMS described how a lack of perceived personal risk and ongoing denial around the diagnosis of MS within the family could influence engagement in prevention:

"I think that is a big thing for a lot of people, because you're the parent, you've created me, so they created something that's not quite right. And I think on a cultural level and a black family level, it's like, you know, it's all about the genes, for want of a better way of putting it." (pwMS)

PwMS shape information flow and FDR engagement

Information shared within families was sometimes shaped by personal experiences, leading to some accounts that could be subtly biased:

“We get everything obviously secondary from my mum and how she receives information is different to potentially how it’s construed. Maybe if she’s in a good frame of mind, she might view it as positive. Maybe if a doctor’s used a specific word and she’s latched onto that.” (FDR)

Information was selectively shared by pwMS, who chose both what to disclose and which relatives to involve, shaping potential future prevention research participation:

“I’d forward it to my sister, but I don’t know if I’d bother forwarding it to my mum” (pwMS)

Information flow was also influenced by the nature of the study itself, with more invasive procedures less likely to be shared with family members. Alongside this, family dynamics and encouragement of participation could influence decision-making, with potential implications for informed-consent processes:

“If it’s not going to impact your day-to-day stuff, then just do it. If it means just taking a few tablets, if it means popping into the hospital for the odd infusion / injection, then go on, do it. Do it for me. That kind of stuff. But, I mean, I would encourage him.” (pwMS)

Need for information starting point and increased visibility

For FDRs in particular, engaging in information about MS online could feel overwhelming, with many unsure where to begin or how to judge the reliability of what they found. In contrast, pwMS tended to feel more confident in knowing where to access information and how to navigate available resources:

“I think it’s just good sources, and I feel like there are a fair amount, you’ve just got to know where to look. But then, usually, the hospital will advise you of the best places to look.” (pwMS)

However, both pwMS and FDRs expressed concerns about the visibility of MS-related information, particularly material relating to risk and prevention, which was often perceived as difficult to locate or not clearly signposted. For FDRs who were less likely to be within the MS networks, this lack of visibility could lead to implications for study recruitment:

“I don’t always see information about these sorts of studies. My dad tagged me in this one, but I guess maybe making the studies more, just getting more eyes on them.” (FDR)

When participants did access information on risk factors, it felt inconsistent and confusing, with misinformation and conflicting information online further complicating access. This led to burden and overwhelm, with participants highlighting the need for streamlined, reliable resources:

“I don’t think there has been one go-to source of truth that I know is there that would tell me what I need to know, including about risk or risk profiles.” (FDR)

Alongside this, difficulty locating resources online limited information sharing, contributing to a sense of burden:

“I’m giving myself a bit of a hard time for not communicating more to my kids and my family but at the same time I think where is that link? I’m sure I’ve seen something but I just can’t quite access it because I can’t find it and I don’t have a huge amount of time to spend trawling through.” (pwMS)

Individual information needs

Information preferences differed considerably, with several participants describing how medical and scientific jargon in both written resources and professional communication was difficult to engage with and understand:

“If you can avoid the jargon as a doctor, please avoid it, but then it doesn’t mean in the process of removing the jargon, you leave out vital information. I mean, online and ChatGPT still gives me quite an amount of information without using jargon, so it’s very possible.” (FDR)

Some participants preferred a direct information related to risk, including risk statistics, without additional positive messaging. For others, such information would heighten anxiety, and they would instead prefer peer-based, lived experience discussions:

“I'd say the only reason why I prefer YouTube and Facebook community, and my doctor is because there is presence of the human presence. I'll put it that way. Because you're not just reading an article, you are hearing the experiences straight from somebody who is currently going through the same thing you are going through.” (pwMS)

Information targeted at FDRs to provide guidance, including foundational information about MS, how to support loved ones, and further information about risk, was identified as a key resource. Participants highlighted the need for information that is both tailored and representative, so that future messaging around risk and prevention speaks meaningfully to the whole MS community:

“They need to be aware of cultural issues, look at their audience, is it predominantly Asian or is it a mixture? So, you've got to make sure that who you are talking to, and you are aware of those cultures, and have the people in front, talking to them, people who come from that community, who actually understand it.” (FDR)

Discussion

Overview of study findings

These findings report the current challenges faced by participating pwMS and FDRs surrounding MS risk information and communication. This includes managing uncertainty, with pwMS and FDRs struggling to make sense of risk and prevention, fluctuating anxiety around who is considered ‘at risk’, and uncertainty about the significance and modifiability of risk factors. FDRs were more likely to avoid information related to MS as a coping mechanism to manage anxiety, whereas pwMS were often more confident in researching and gaining knowledge. Views on the modifiability of risk factors varied, with feelings of

responsibility, control, and blame shaping how both pwMS and FDRs understood risk factors. Conflicting health information complicated understanding of MS risk further, with pwMS often relied on to provide information to their families. PwMS and FDRs avoided conversations particularly around risk to prevent distress, with many participants meeting additional challenges to communication, including cultural stigma and misconceptions, and complex family dynamics.

Overall, there was consensus of hopefulness for future prevention initiatives. However, questions were raised about how primary prevention is possible without a clear, known cause and the feasibility of secondary prevention given existing systemic barriers. PwMS had a significant impact on FDR engagement, filtering and selectively sharing information with family members, and raised about invasive measures. Ultimately, this study highlighted the need for transparent, easily accessible information about MS risk and increased visibility. This information needs to be tailored and personalised to support differing informational needs, with widely varying preferences across the sample unlikely to be met through a blanket approach.

Interpretation and context in the literature

Many of the challenges highlighted in this study reflect findings reported for other conditions, with uncertainty a central theme. Risk and prevention are consistently misunderstood across chronic conditions, with phenomena such as optimism bias (where risk is underestimated), and pessimism bias (where risk is overestimated), impacting how accurately individuals interpret their own risk and respond with health behaviours[23]. For example, a prospective longitudinal study exploring outcomes of 11 chronic conditions (including diabetes, cancer, and arthritis or rheumatism) found that optimism bias was significantly associated with an increased risk of developing a chronic condition, with lifestyle mediating this association[23]. Within our sample, participants described a lack of clear, understandable information about the risk of developing MS, with some underestimating and others overestimating their risk. This is likely due to the complexity of MS risk, with no single factor solely linked to disease onset[4]. Many participants expressed a lack of confidence in understanding the nuances of MS risk, which could affect engagement in prevention studies and health behaviours. Similarities were found in beliefs about diabetes, colon cancer, and heart disease, with greater uncertainty about risk judgements associated with lower engagement in preventive behaviour such as exercise[24].

Furthermore, our study identified that participants' personal beliefs and coping shaped risk factor perceptions, for example, seeking reassurance from risk factors that did not align with their traits (e.g. MS being more prevalent in women[4]) or feeling they need to reach the age their relative developed MS to feel less 'at risk'. This is reflected in the literature, personal experience, identification, and future plans shaping the value attributed to risk[25]. This mechanism can take multiple forms including individuals comparing their traits to their affected relatives' physical characteristics, lifestyle, and personality, in turn influencing personal risk perception and health behaviour[25]. This highlights that individuals do not interpret risk information purely scientifically, with prior beliefs influencing how 'at risk' they feel.

Therefore, risk information needs to be relatable and contextualised to enhance understanding and reduce perceived complexity.

Uncertainty could also be linked to how existing MS-related information is presented and interpreted. A systematic review demonstrated limited MS risk knowledge when exploring pwMS' perceptions of risks related to treatments and disease progression[26]. Although this did not directly explore perceptions of risk factors, the study highlights the complexity of health information and identified a correlation between higher educational attainment and higher MS knowledge or risk knowledge[26]. This could link to health literacy, with lower levels of education and limited health literacy associated[27]. In saying this, our sample of pwMS were research active and most had accessed a degree-level education. Despite this, difficulties interpreting MS-related information, overly scientific jargon, and using AI to make information more accessible were all reported. This further emphasises the importance of communication strategies that prioritise accessibility through lay summaries that retain key information.

Responsibility, control, and blame were key concepts linked to understanding MS risk, with many participants describing the difficulties of reflecting on MS development, modifiable risk factors, and health guidelines. These concepts have been identified in other conditions, with genetic risk sometimes downplayed as a coping strategy, and control and autonomy a consistent theme related to coping[25]. The absence of defined, actionable steps to reduce MS risk was associated with control in our sample. In a hypothetical genetic testing study exploring public perceptions, medical management and communication were ranked as most important, including treatments, seeing a doctor, and participation in research studies to find a treatment[28]. This highlights a key challenge within MS risk communication, where communication without actionability could cause increased emotional distress and isolate individuals[4]. MS research is advancing, with the identification of prodromal phases and high-risk groups; however, clinical practice cannot introduce risk-reduction steps for individuals[29]. This gap complicates risk communication and the potential for emotional burden; however, integration screening within research could enable action and increase the likelihood of early detection[29].

However, our sample identified systemic factors, such as inequalities in access to care, as barriers to effective early detection. This was reflected in the Atlas questionnaire focused on MS diagnosis, where lack of awareness of MS symptoms among healthcare professionals and lack of readily available specialist MS neurologists impacted timely diagnosis[30]. Furthermore, our participants described experiences with stigma and misconceptions from healthcare professionals delaying their diagnosis of MS. This highlights the need for educational resources to reduce barriers to early detection and create consistent care. Lack of awareness of MS symptoms among the general public was the most reported barrier to early diagnosis[30]. There were varied levels of awareness in our sample among FDRs about MS beyond their personal experience within their family, especially regarding the benefits of early detection. This stresses the importance of increased public messaging about the different forms of prevention, particularly targeted towards at-risk populations.

Family communication about risk was frequently avoided, especially amid complex family dynamics. In genetic conditions, identified motivators for family communication include understanding the disease, alongside the associated treatment and reproductive implications; individual factors such as age, personal perceived risk and responsibility; family factors such as physical proximity, openness, and flexibility; and sociocultural factors such as gender, and cultural notions of kinship and family structure[31]. There were some similarities within our sample, such as confidence in MS understanding dictating likelihood to communicate about MS risk; cultural factors such as avoiding 'taboo' conversations; and family systems that were more open and flexible being more likely to speak about risk. Further support is warranted to guide these conversations, alleviate pressure on pwMS and FDRs, consider intersectional factors that influence risk communication, and encourage open conversations.

There was a strong belief in the sample that primary prevention was not possible without a known cause of MS. This understanding could be reflective of public awareness of preventative measures for MS, with a survey identifying that compared to dementia and Parkinson's disease, respondents had the least awareness of MS preventative measures[32]. Because steps can be taken toward prevention without a known cause[33], it is crucial to increase public awareness of current research progress to inform future prevention studies, particularly those involving FDRs. This study identified several barriers to participation, including the invasiveness of research methods and indirect recruitment methods; for example, an overreliance on pwMS to disseminate study information to FDRs, which results in inconsistent communication. In RA, lifestyle changes were preferred over pharmacologic interventions for risk reduction[34], with the use of invasive measures and increased participation burden such as time limiting recruitment[35]. Additionally, our study identified that pwMS filter information and are selective in what they share with FDRs based on factors such as perceived relatedness and burden. Future prevention studies should ensure that family dynamics are considered when sharing study information and informed consent processes.

Information preferences varied considerably, with how MS risk and prevention is communicated to the public being key to interpretation and action. Gain framing (e.g. you will live longer) versus loss framing (e.g. smoking causes cancer) yield different responses, with some of our participants preferring positive framing, although negative framing is considered more effective for behaviour change[36]. Where risk is difficult to understand, our study emphasised the importance of clear, relatable information that is streamlined to reduce burden. The literature supports the benefits of tailoring information based on characteristics, providing decision aids, and using evidence-based leaflets[36]. Further efforts are needed to increase the visibility and accessibility of MS risk information, particularly by designing resources that recognise individual differences in preferences, culture, and family dynamics.

Strengths and limitations

We conducted an in-depth exploration of perceptions and attitudes towards MS risk and prevention, providing novel insights into a complex topic. Most transcripts were double-coded, which broadened analytical perspectives. Furthermore, collaboration with PPI advisors and efforts to purposively sample ethnicity enhanced representation and ensured the study accurately reflected lived experience. However,

due to time constraints, we were unable to balance ethnicity equally, which is a limitation of the study. Additionally, our study sample was female-dominant, which could be consistent with the higher prevalence of MS among women[4], or explained by women being more likely than men to communicate about risk[31].

Conclusion

This study provides in-depth insights into perceptions of MS risk and prevention among pwMS and FDRs. Action is required to provide accessible MS risk information that can be engaged with flexibly, including further support to guide risk communication within families. Resources need to be tailored, allowing space for personalisation and ensuring information remains relevant. Future research should gather perspectives of MS risk and prevention in healthcare professionals, such as general practitioners, MS nurses, and neurologists to progress towards synthesised guidance and messaging.

Declarations

Competing Interests:

AT has received research support from the UK MS Society, NIHR, ADR UK, Roche, Merck, Genzyme Sanofi, Barts Charity and the Horne Family Charitable Trust. She has received speaker honoraria from Novartis, Merck, Roche and Neuraxpharm. The following authors have nothing to declare: IS, LW, ML, AG, MM, GG, WB, RD, MF.

Ethical Approval and Consent to Participate:

Ethical approval was obtained from Queen Mary, University of London Ethics Committee (QME25.0942). The research was carried out in accordance with the guidelines and regulations of the Queen Mary, University of London Ethics Committee. Informed consent was obtained from all individual participants included in the study. All participants were aged 18 or over.

Consent for Publication:

Informed consent to publish was obtained from all participants, including consent for the publication of anonymised verbatim quotations. All quotations have been anonymised and de-identified to prevent identification of individual participants.

Data Availibility

Data will be shared upon reasonable request by the corresponding author.

Funding:

This work was supported by The MS Society grant number 216.

Author Contribution

Isabelle Symes: conceptualisation, methodology, investigation, formal analysis, writing – original draft, writing – review and editing. Lucy Wright: formal analysis, writing – review and editing. Mark Leach: conceptualisation, methodology, formal analysis, writing – review and editing. Anisha Gangotra: conceptualisation, methodology, formal analysis, writing – review and editing. Marion McAllister: writing - review and editing. Gavin Giovannoni: writing – review and editing. Will Brown: writing – review and editing. Ruth Dobson: conceptualisation, writing – review and editing. Marie Falahee: conceptualisation, methodology, formal analysis, writing – review and editing, supervision. Alison Thomson: conceptualisation, methodology, formal analysis, writing – review and editing, supervision, funding acquisition.

Acknowledgement

We would like to thank all the participants for taking their time to contribute to this study.

References

1. Jakimovski D, Bittner S, Zivadinov R, Morrow SA, Benedict RH, Zipp F, Weinstock-Guttman B. Multiple sclerosis. Lancet Elsevier. 2024;403(10422):183–202. PMID:37949093.
2. MS in the UK | MS Society. Available from: https://www.mssociety.org.uk/what-we-do/our-work/our-evidence/ms-in-the-uk[accessed Feb 11, 2026].
3. Marcus R, What Is Multiple. Sclerosis? JAMA 2022;328(20):2078. 10.1001/jama.2022.14236
4. Dobson R, Kreft KL, Jacobs BM, Brown JWL, Thomson A, Nicholas R, Walton C, Narendran P. Towards primary prevention of multiple sclerosis. Nat Rev Neurol Nat Publishing Group. 2025;1–14. 10.1038/s41582-025-01164-w.
5. Bebo B, Coetzee T, Gray E, Helme A, Kanellis P, Landsman D, Mai M, Martinez de la Cruz B, Morahan J, Plassart E, Pickrell B, Rawlings S, Skovgaard L, Zaratin P, Rechtman L, Publications Ltd STM. 2024Sept 1;30(10):1363–9. doi: 10.1177/13524585241265961.
6. Priority 2 from the Multiple Sclerosis PSP | NIHR JLA. Available from: https://www.jla.nihr.ac.uk/priority-setting-partnerships/multiple-sclerosis/top-10-priorities/priority-2-from-the-multiple-sclerosis-psphtm[accessed Feb 11, 2026].
7. Herold KC, Bundy BN, Long SA, Bluestone JA, DiMeglio LA, Dufort MJ, Gitelman SE, Gottlieb PA, Krischer JP, Linsley PS, Marks JB, Moore W, Moran A, Rodriguez H, Russell WE, Schatz D, Skyler JS, Tsalikian E, Wherrett DK, Ziegler A-G, Greenbaum CJ. An Anti-CD3 Antibody, Teplizumab, in Relatives at Risk for Type 1 Diabetes. N Engl J Med Mass Med Soc. 2019;381(7):603–13. 10.1056/NEJMoa1902226.

8. Quinn LM, Boiko O, Elliott J, Randell M, Litchfield I, Boardman F, Dias RP, Greenfield SM, Narendran P. Treatment acceptability for disease-modifying therapy for type 1 diabetes (T1D)—Views from parents of children with presymptomatic T1D. Volume 27. Diabetes Obes Metab John Wiley & Sons, Ltd; 2025. pp. 6059–67. 1010.1111/dom.16639.
9. Roberts JS, Patterson AK, Uhlmann WR. Genetic testing for neurodegenerative diseases: Ethical and health communication challenges. Neurobiol Dis 2020 July 1;141:104871. 10.1016/j.nbd.2020.104871
10. Radu A-F, Bungau SG. Management of Rheumatoid Arthritis: An Overview. Cells. 2021;10(11):2857. PMID:34831081.
11. van Steenbergen HW, Cope AP, van der Helm-van Mil AHM. Rheumatoid arthritis prevention in arthralgia: fantasy or reality? Nat Rev Rheumatol Nat Publishing Group. 2023;19(12):767–77. 10.1038/s41584-023-01035-y.
12. Cope AP, Jasenecova M, Vasconcelos JC, Filer A, Raza K, Qureshi S, D'Agostino MA, McInnes IB, Isaacs JD, Pratt AG, Fisher BA, Buckley CD, Emery P, Ho P, Buch MH, Ciurtin C, van Schaardenburg D, Huizinga T, Toes R, Georgiou E, Kelly J, Murphy C, Prevost AT, Norton S, Lempp H, Opena M, Subesinghe S, Garrood T, Menon B, Ng N, Douglas K, Koutsianas C, Cooles F, Falahee M, Echavez-Naguicnic I, Bharadwaj A, Villaruel M, Pande I, Collins D, Pegler S, Raizada S, Siebert S, Fragoulis G, Guinto J, Galloway J, Rutherford A, Barnes T, Jeffrey H, Patel Y, Batley M, O'Reilly B, Venkatachalam S, Sheeran T, Gorman C, Reynolds P, Khan A, Gullick N, Banerjee S, Mankia K, Jordan D, Rowlands J, Starmans-Kool M, Taylor J, Nandi P, Sahbudin I, Maybury M, Hider S, Barcroft A, McNally J, Kitchen J, Nisar M, Quick V. Abatacept in individuals at high risk of rheumatoid arthritis (APIPPRA): a randomised, double-blind, multicentre, parallel, placebo-controlled, phase 2b clinical trial. Lancet. 2024;403(10429):838–49. 10.1016/S0140-6736(23)02649-1.
13. Falahee M, Simons G, Buckley CD, Hansson M, Stack RJ, Raza K. Patients' Perceptions of Their Relatives' Risk of Developing Rheumatoid Arthritis and of the Potential for Risk Communication, Prediction, and Modulation. Arthritis Care Res. 2017;69(10):1558–65. 10.1002/acr.23179.
14. Siddle HJ, Chapman LS, Mankia K, ZÄƒbÄƒlan C, Kouloumas M, Raza K, Falahee M, Kerry J, Kerschbaumer A, Aletaha D, Emery P, Richards SH. Perceptions and experiences of individuals at-risk of rheumatoid arthritis (RA) knowing about their risk of developing RA and being offered preventive treatment: systematic review and thematic synthesis of qualitative studies. Ann Rheum Dis. 2022;81(2):159–68. 10.1136/annrheumdis-2021-221160.
15. Chapman LS, Siddle HJ, Serban S, Mankia K, Rooney CM, Mustufvi Z, Pini S, Vinall-Collier K. What is my risk really? a qualitative exploration of preventive interventions among individuals at risk of rheumatoid arthritis. Rheumatol Adv Pract. 2024;8(2):rkae023. PMID:38495430.
16. Simons G, Schölin Bywall K, Englbrecht M, Johansson EC, DiSantostefano RL, Radawski C, Veldwijk J, Raza K, Falahee M. Exploring preferences of at-risk individuals for preventive treatments for rheumatoid arthritis. Scand J Rheumatol. 2023Sept;52(5):449–59. PMID:36178461.

17. Wells I, Zemedikun DT, Simons G, Stack RJ, Mallen CD, Raza K, Falahee M. Predictors of the likelihood that patients with rheumatoid arthritis will communicate information about rheumatoid arthritis risk to relatives: A quantitative assessment. Patient Educ Couns 2023 July 1;112:107713. 10.1016/j.pec.2023.107713
18. van Boheemen L, ter Wee MM, Seppen B, van Schaardenburg D. How to enhance recruitment of individuals at risk of rheumatoid arthritis into trials aimed at prevention: understanding the barriers and facilitators. RMD Open EULAR; 2021;7(1). PMID:10.1136/rmdopen-2021-001592
19. Laitinen AW, Tozlu C, Roostaei T, Diallo F, Onomichi K, Son J, Xia Z, De Jager PL. A Prospective Study of Individuals at Risk of Multiple Sclerosis Informs the Design of Primary Prevention Studies. Ann Clin Transl Neurol n/a(n/a). 10.1002/acn3.70340
20. O'Brien BC, Harris IB, Beckman TJ, Reed DA, Cook DA. Standards for Reporting Qualitative Research: A Synthesis of Recommendations. Acad Med 2014 Sept 1;89(9):1245–1251. 10.1097/ACM.0000000000000388
21. Braun V. Reflecting on reflexive thematic analysis. Qual Res Sport Exerc Health Routledge. 2019;11(4):589–97. 10.1080/2159676X.2019.1628806.
22. Byrne D. A worked example of Braun and Clarke's approach to reflexive thematic analysis. Qual Quant 2022 June 1;56(3):1391–1412. 10.1007/s11135-021-01182-y
23. Zhong Y, Cao J. Risk perception bias, lifestyle, and chronic disease risk in the middle-aged and older Chinese population: results of a national prospective longitudinal study. BMC Public Health. 2026;26:434. PMID:41484971.
24. Orom H, Biddle C, Waters EA, Kiviniemi MT, Sosnowski AN, Hay JL. Causes and consequences of uncertainty about illness risk perceptions. J Health Psychol SAGE Publications Ltd; 2020 July 1;25(8):1030–1042. 10.1177/1359105317745966
25. Oliveri S, Pravettoni G. Capturing how individuals perceive genetic risk information: a phenomenological perspective. J Risk Res Routledge. 2018;21(2):259–67. 10.1080/13669877.2017.1281333.
26. Smith E, Langdon D. A systematic review to explore patients' MS knowledge and MS risk knowledge. Neurol Sci 2024 Sept 1;45(9):4185–4195. 10.1007/s10072-024-07541-5
27. Kickbusch I. Health Literacy, the solid facts. Geneva: World Health Organization; 2013. ISBN:978-92-890-0015-4.
28. Seiffert DJ, McCarthy Veach P, LeRoy B, Guan W, Zierhut H. Beyond medical actionability: Public perceptions of important actions in response to hypothetical genetic testing results. J Genet Couns. 2019;28(2):355–66. 10.1002/jgc4.1048.
29. Tremlett H. High-risk populations should be screened for MS: Yes. Mult Scler Houndmills Basingstoke Engl 2025 July 8;31(9):1032–1034. PMID:40625186.
30. Solomon AJ, Marrie RA, Viswanathan S, Correale J, Magyari M, Robertson NP, Saylor DR, Kaye W, Rechtman L, Bae E, Shinohara R, King R, Laurson-Doube J, Helme A. Global Barriers to the Diagnosis of Multiple Sclerosis. Neurology. 2023;101(6):e624–35. PMID:37321866.

31. Abad PJB. Family Communication of Genetic Risk: What is it and Why does it Matter? Acta Med Philipp 2025 June 30;59(8):7–15. PMID:40755559.
32. Thomson A, Kenten C, Banerjee S, Browning S, Pouncey T, Horne R, Cooper C. Prevention Is Better Than Cure: Public Understanding of Preventing Neurodegenerative Disorders. Int J Geriatr Psychiatry. 2025;40(1):e70038. 10.1002/gps.70038.
33. Preventing MS. not so far-fetched? | MS Society. Available from: https://www.mssociety.org.uk/support-and-community/community-blog/preventing-ms-not-so-farfetched[accessed May 20, 2026].
34. Simons G, Stack RJ, Stoffer-Marx M, Englbrecht M, Mosor E, Buckley CD, Kumar K, Hansson M, Hueber A, Stamm T, Falahee M, Raza K. Perceptions of first-degree relatives of patients with rheumatoid arthritis about lifestyle modifications and pharmacological interventions to reduce the risk of rheumatoid arthritis development: a qualitative interview study. BMC Rheumatol. 2018;2:31. PMID:30886981.
35. Klompstra L, Strömberg A, Jaarsma T, Hendriks JM. Challenges and strategies for effective recruitment and retention of participants in clinical research studies. Eur J Cardiovasc Nurs 2025 July 1;24(5):808–812. 10.1093/eurjcn/zvae158
36. Naik G, Ahmed H, Edwards AG. Communicating risk to patients and the public. Br J Gen Pract Br J Gen Pract. 2012;62(597):213–6. PMID:22520906.

Supplementary Files

This is a list of supplementary files associated with this preprint. Click to download.

- SupplementaryInformation1.docx
- SupplementaryInformation2.docx