Research Involvement and Engagement

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Enhancing patients' role in scientific writing: insights from a global participatory approach with people with multiple sclerosis

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Abstract

Introduction This study aims to describe a participatory process by investigating the perceptions and expectations of people with multiple sclerosis (pwMS) toward the scientific writing (SW) process and the role of patient engagement and quality of life in influencing them.

Methods A two-phase, multi-methods study was conducted inspired by the MULTI-ACT model. Four co-creation workshops were organized, and the results were used to design a survey, which was translated into eight languages and distributed internationally to 1120 patients. The results from the workshops and the survey were collaboratively used to develop a model for engaging patients in SW.

Results Participants expressed a willingness to share their unique experiences of the disease, contribute ideas and words to the project, and engage in research-related problem-solving. The main barriers to patient engagement in SW were identified as physical, psychological, and technical. The survey sample consisted of pwMS primarily from Italy (28.5%), was predominantly female (73.7%), with a mean age of 50.3 years and an average MS diagnosis duration of 13.5 years. Among the participants, 45% had never participated in research initiatives, 89% had never been an author of a scientific publication, and 51% expressed interest in future participation.

Conclusion Patients' disease awareness and their perception of quality of life may influence their predisposition towards research and SW. Patient co-authors clearly articulated their perspectives on the essential factors required for contributing to the publication process. A more sensitive approach should be adopted in order to take into account the psychosocial conditions of people with multiple sclerosis and what may hinder their participation in research and in writing scientific publications in order to really guarantee equal access to all.

Plain English Summary

Scientists are increasingly recognizing the value that people with lived experience of an illness bring to medical research, including their contributions to planning, managing, and authoring scientific publications. This study involved patients and researchers in a participatory process to highlight the benefits of patient participation in research. A global survey completed by over 1,000 people with Multiple Sclerosis (MS) from diverse backgrounds

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aimed to understand their engagement in research and the factors influencing their participation. The study revealed several barriers that prevent people with progressive MS from fully engaging in the research process. Many participants cited severe fatigue, limited energy, physical isolation, and poor mental health as major obstacles. Perceived quality of life significantly impacted their interest and willingness to participate in research and their confidence in contributing to scientific authorship. Additionally, systemic barriers discouraged patient engagement in research and scientific writing: the need for fluency in English, challenges arising from cultural diversity, lack of confidence in using scientific terminology, and the rigid formats of traditional research and publishing. Poor communication between scientists and patients and a perceived lack of inclusivity also hindered participation. To address these issues, the paper advocates for several measures to promote inclusivity by setting clear communication goals, providing support to overcome language barriers, and creating a support network to address individual patient needs. Institutional, funding, regulatory, and publishing formats should become more flexible and collaborative. Systemic changes are needed to make patient engagement meaningful, accessible, and effective, fostering a respectful two-way dialogue between scientists and patients.

Keywords Authorship, Multiple sclerosis, Participatory governance, Patient author, Patient engagement, Responsible research innovation, Scientific publication authorship

Key summary points

Why carry out this study?

- People with chronic conditions, such as Multiple Sclerosis (MS), are often excluded from the scientific writing process, which limits the impact and relevance of research and their engagement.
- Engaging patients throughout the research cycle, including scientific writing, can enhance research outcomes and communication.
- The study aimed to identify the barriers and opportunities for involving patients with progressive MS in scientific writing and explore their potential roles in the process.

What was learned from the study?

- Among the participants, 45% had never participated in research initiatives, 89% had never been an author of a scientific publication, and 51% expressed interest in future participation.
- Severe fatigue, poor mental health, and physical isolation are major barriers for patients with MS to engage in research and scientific writing.
- Systemic barriers, such as the need for fluency in English, a lack of confidence in using scientific terminology, and rigid publishing formats, exclude non-academic contributions.
- Adopting principles of patient engagement and flexible, inclusive research and publishing practices can bridge the gap between patient engagement in research and their participation as scientific authors, making the process more equitable and impactful.

Background

Engaging people with chronic conditions in scientific writing has gained significant attention in recent years; however, there remain key gaps in understanding how this inclusion might evolve to more effectively value patients' contributions [1]. Central to this discussion is patient engagement, which has been widely examined for its role in promoting health outcomes, psychological adaptation, and quality of life across disease areas [2, 3]. Traditionally defined as individuals' psychological readiness to take responsibility for managing their condition—entailing a reconfiguration of personal identity and care-related roles toward increased proactivity [4, 5]—patient engagement can be amplified by engaging patients in research tasks beyond their own treatment, including scientific writing [6–8].

Patient engagement in scientific writing refers to the participation of patients in drafting and publishing articles about their experiences, acknowledging them as primary and indispensable sources of contextual knowledge [9]. This discussion is framed by the broader debate on integrating experiential knowledge—personal, subjective, and context-dependent—with scientific knowledge that is systematically generated through empirical evidence and the scientific method [10–13]. While experiential knowledge is increasingly recognized for its practical and emotional insights into illness and healthcare interactions, a lingering form of "epistemic injustice" remains, wherein patients' voices are historically underrepresented or devalued [14, 15]. Overcoming this requires an equitable approach to knowledge creation that embraces patients' lived experiences, including when producing scientific literature.

Various efforts are underway to reduce such imbalances; for example, the British Medical Journal (BMJ) mandates explicit statements on patient and public involvement in submissions to BMJ Open, echoing

Charlton's principle of "Nothing About Us Without Us" [16], to promote transparent reporting and encourage the widespread adoption of patient engagement frameworks in research practices and scientific writing [17]. These measures address the urgent need for inclusive research practices, but the field still grapples with practical challenges, such as adapting authorship guidelines to acknowledge patient partners meaningfully without reverting to tokenistic participation [18, 19]. Additionally, each study context is unique, so frameworks for scientific writing must be tailored to fit not only methodological requirements but also patients' psychological predisposition—namely, the extent to which they feel ready and motivated to engage [20, 21].

In line with these premises, it is likely that individuals affected by chronic conditions can contribute to the discourse and represent themselves in various ways when considering patient engagement and scientific writing [8]. These insights are especially pressing in complex chronic diseases like progressive Multiple Sclerosis (MS), where dynamic illness trajectories and individual coping strategies make patient perspectives critical for measuring disease progression [21] and quality of life [22]. In turn, inviting people with MS (pwMS) to contribute to scientific publications can serve as a catalyst for broader research participation and identity reconfiguration, further underscoring the urgency of establishing best practices for patient engagement in writing. Also, emerging initiatives showcase how deeper, more cohesive collaboration between patients and researchers can be pursued. Although there is growing recognition that patients' direct contributions can advance the scientific debate, an array of barriers—ranging from time constraints and unclear authorship policies to potential reluctance from journal editors and research teams—continues to hinder the integration of patients as authors [24–28]. Brain health research, informed by principles of European Responsible Research and Innovation (RRI), points to a path forward by promoting multistakeholder engagement from project design to publication, thereby harnessing patients' firsthand experiences while also valuing intellectual contributions from diverse partners [29, 30]. This approach aims to realign academic priorities with patient and community values, establishing a shared research mission and redefining authorship as a collaborative process grounded in equity, diversity, and inclusion.

Despite increasing calls for patient engagement, there is scant empirical research on the practical and psychological factors that influence patients' willingness and ability to serve as co-authors in scientific publications. This lack of guidance is particularly evident in progressive MS, a condition requiring sustained patient involvement to capture dynamic experiences of disease progression. While national patient organizations, governments, industry, and researchers have all highlighted quality of life (people experiential knowledge) as a pivotal element for more holistic management, there remains a need for practical models and frameworks that encourage continuous patient engagement in scientific writing [23]. Progressive forms of multiple sclerosis (MS) affect more than 1 million individuals globally. Despite positive developments in the field, major gaps persist in both the treatment and management of progressive disease. Collective efforts by the International Progressive MS Alliance [23], national patient organizations, government, and industry together with researchers and clinicians and patients have drawn much needed attention to the challenges of progressive MS. In this framework, the International Progressive MS Alliance initiative recognizes the crucial importance of guiding effective participatory governance of people affected by MS in research by applying an innovative model in line with the Responsible Research Innovation (RRI) principle promoted by the European Community. Hence, an Engagement Coordination Team (ECT), including people affected by MS, was established to support the International Progressive MS Alliance initiative to integrate the unique experience of living with MS into the research agenda initiative. The International Progressive MS Alliance entered into a collaboration with the Italian MS Foundation, coordinator of the MULTI-ACT EU Project and EngageMinds HUB to study people with progressive MS perspectives on the roles they can and should have in scientific writing. Building on established guidance for applying the International Committee of Medical Journal Editors (ICMJE) criteria to patient partners [25], this study adopts a participatory approach to examine the barriers and opportunities for patient engagement in scientific writing among individuals with progressive MS. Specifically, we explore how changes in role identity and psychological predisposition toward the disease influence these factors. Given the unique course and symptom burden of MS, we also examine perceived quality of life as a potential determinant of patients' willingness to engage in research and publication. Rather than limiting the scope to a few "expert" patients, our study aims to involve a broader, more representative community —a foundational skill in meeting equity, diversity, and inclusion needs through RRI principles. In line with these objectives, we address the following research questions: (1) What barriers and opportunities do individuals with progressive MS perceive in engaging in scientific writing? (2) How do changes in role identity and psychological predisposition toward the disease shape their willingness to participate? (3) In what ways does perceived quality of life influence their engagement and ability to contribute as co-authors? Ultimately, this paper reflects on how processes of scientific writing and publishing should evolve to better

acknowledge, integrate, and value the contributions of patients with progressive MS.

Methods

Study design

The current study adopted a mixed-methods participatory approach in line with the MULTI-ACT Collective Research Impact Framework [30]. This model promotes the engagement of patients in all stages of the research process, addressing a critical factor in meeting the research objectives (being involved in the early stages of the research). In line with the MULTI-ACT model, we initially adopted a qualitative approach to bring researchers and patients together to discuss and share ideas on how to structure the work, determine the number of meetings to organize, and divide tasks. A preliminary meeting was held to introduce the concept and establish the working methodology. Subsequently, we followed a patient-partner approach [10], where some patients contributed to defining the study design, data collection, data analysis, and the writing of the article. Moreover, interactive communication—ranging from informal contacts via telephone and e-mail to participation in meetings and discussions through focus groups—was implemented. This form of communication allowed participants to engage in the process, offer advice, and deliberate with each other. We viewed dialogues as mutual learning opportunities and to lay the foundation for the integration of patients's perspectives. Conversations throughout the process were often informally captured, for example, through meeting notes, and were recorded as proof of the discussions and included in the analysis [31].

In more details, the study design was articulated in two phases: (i) the co-creation workshops and (ii) the consensus survey. This study has been performed in accordance with the Helsinki Declaration of 1964, and the ethical approval for the involvement of human subjects in this study was granted by the Catholic University of Sacred Heart Research Ethics Committee (reference number 17–24). Informed consent was obtained from participants before the start of the survey, allowing respondents to choose whether to participate, and no incentives were provided to participants. Moreover, building on the ICMJE criteria and elaborated guidance, two authorship agreements were developed together (one for pwMS and one for the other members; included in Appendix 1 and 2) and signed by the workshop members together with the privacy policy. The authors of the manuscript, including patients, signed the authorship agreement to ensure that they understood their authorship responsibilities and how to avoid unethical practices.

Phase 1 – co-creation workshops

Four co-creation workshops were conducted in line with the collaborative framework of the MULTI-ACT model to discuss spontaneous representations, barriers, and opportunities for engaging patients in scientific writing [30]. Tools like workshops and focus groups are recognized as successful tools for ensuring patient engagement in research and for enhancing their role as patient partners, and these tools promote discussion and the sharing of ideas, facilitate interaction among participants, and foster greater equity among roles [31].

Participants

The discussion group comprised four individuals with progressive MS, two patient-advocacy researchers coordinating patient engagement programs, and two academic researchers and psychology experts in patient engagement. All the researchers possess knowledge of MS, expertise in Responsible Research Innovation participatory governance models, and proficiency in scientific writing. Individuals with progressive MS were recruited to ensure a balance in terms of gender, geography, and language.

Procedure

The workshops were conducted online via Microsoft Teams, between March 2023 and February 2024, following the MULTI-ACT model [30] and using qualitative techniques to facilitate collaboration among the participants, enabling the researchers to elicit spontaneous opinions, build consensus on the results, and capitalize on this shared knowledge for the subsequent phases of the study. First, we favored the creation of a welcoming and safe environment. Due to geographical reasons, we had to use an online platform for the discussion, but we opted for informal communication to encourage interaction and minimize hierarchical dynamics among participants. To ensure that every voice was heard, clear rules of respect and active listening were established from the outset, allowing participants to share their experiences without fear of judgment. The moderator effectively encouraged balanced participation, managed potential conflicts, and created a setting where all participants felt comfortable contributing to the discussion. In addition, we utilized open and thought-provoking questions to encourage in-depth discussion and reflection. Broad, non-directive questions were asked to allow participants to freely share their experiences and perspectives. Follow-up prompts were also used to explore topics more deeply, fostering a dynamic and engaging conversation [31, 32]. Finally, the workshop incorporated concept visualization techniques to support participants in organizing and expressing their ideas. We used concept maps, diagrams, and visual aids to illustrate relationships

between key themes and stimulate discussion. This visual approach helped clarify complex concepts, encouraged collaboration, and allowed participants to engage more actively by contributing to the creation of shared representations of their thoughts and experiences [33, 34]. The Mirò platform was used to present tasks during the online discussions and to take notes on the initial emerging results.

The topics of the meetings were selected by the researchers, following the main steps of the scientific writing process from the MULTI-ACT model, ensuring that the insights and notes gathered at each meeting resulted in portions of the text for this article. This approach aimed to deconstruct the traditional figure of the author of scientific publications and reconstruct it in terms of patients' inclusivity (authorship equity), contribution to a scientific publication (authorship contribution), and building and revising the paper [35]. During the first meeting, this structure was discussed and approved by the participants (Fig. 1). Each meeting was organized as follows: an initial open discussion on each topic was elicited through open-ended questions and brainstorming tasks. The second task was designed to facilitate the emergence of statements and related key words (Fig. 2), which were subsequently elaborated and included in the results of this paper. The statements were transcribed by a researcher during the meeting onto Mirò. Finally, the last part of each meeting focused on finalizing items for the survey. A bullet points page was prepared in Mirò for participants to fill with items capturing the essence of the results that emerged during the meeting. Access to the platform was shared among the participants, who were invited to contribute to the discussion during and between the online meetings, enabling them to track all the results emerging from the participatory discussion.

Data analysis

The first author transcribed and analyzed the data using qualitative content analysis [36]. A draft of the emerging themes was created and sent to the participants – here listed as co-authors - to ensure they could review or further elaborate on the themes, including adding new ones if deemed necessary. In this way, the research team aimed to reach a consensus on the analysis and interpretation of the results. As shown in Fig. 1, during each meeting, participants were asked—not only to contribute their experiences regarding patient engagement in research and scientific writing—but also to formulate items that would later be included in the survey extended to a larger cohort of patients in phase two. The items were thus developed by the patients and incorporated into the survey. Through this process, we facilitated the sharing of decision-making power by involving patients in the decision-making process. This allowed decision-making to occur in "real time."

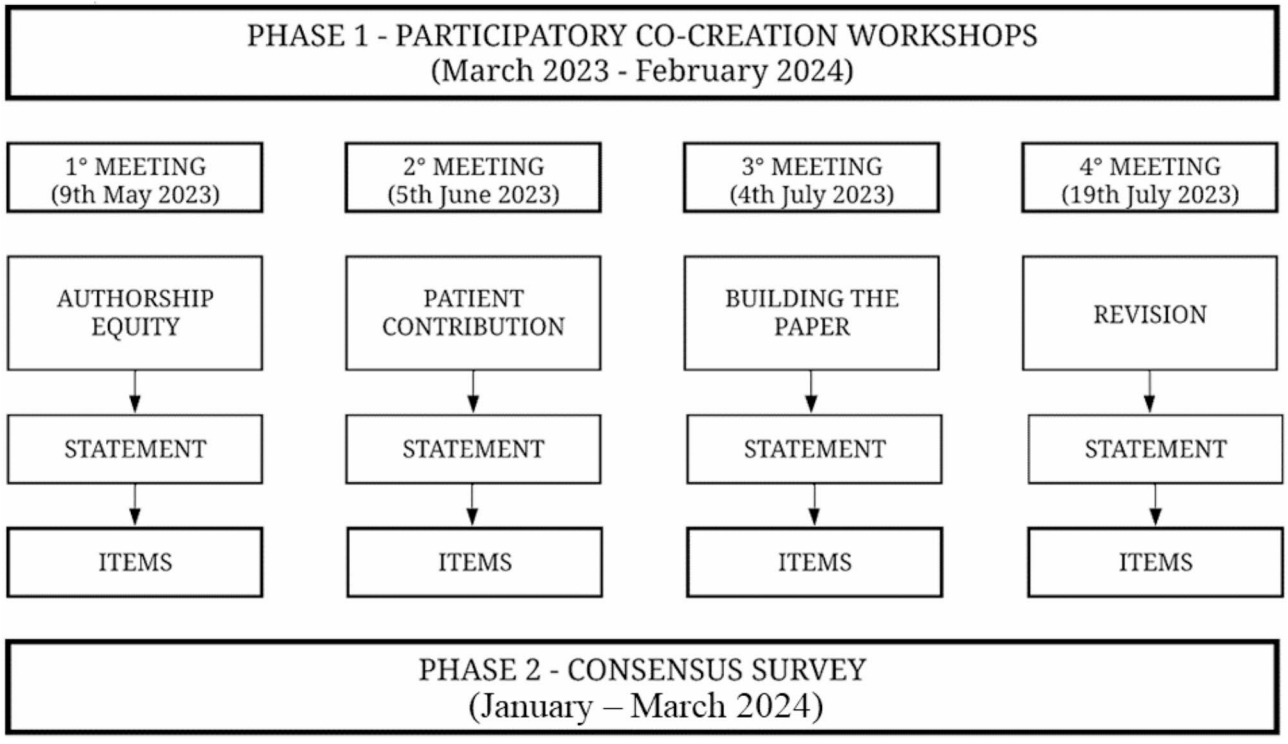

Fig. 1 Patient engagement process in scientific publishing: Structure of the co-creation workshops and the consensus survey

Fig. 2 Patient engagement process in scientific publishing: word cloud generated during the co-creation workshops

Phase 2 - consensus survey

The objective of Phase 2 was to more representative capture the experiences of individuals with progressive MS from various countries regarding the process discussed in the previous phase. Additionally, the study aimed to verify the possible impact of quality of life and patient engagement on changing patients' positions toward research and scientific writing.

Sample

In Phase 2, a cross-sectional study was conducted as an online survey with 1120 patients diagnosed with progressive MS between January and March 2024. Leveraging its international reach, the survey utilized a Computer Assisted Web Interviewing mode provided by the Norstat Group. Participants older than 18 years were enrolled through collaboration with the international network of the Multiple Sclerosis International Federation (MSIF) and the Italian MS Foundation (FISM), who distributed the survey link. Patients were ineligible if they were unable to give informed consent or had a cognitively impaired capacity to complete the survey.

Data collection tools

Based on the results from the previous phase, a survey was developed and translated into eight languages: English, French, Arabic, Italian, Spanish, Polish, German, and Swedish. The questionnaire consisted of 31 items divided into the following four sections (see Appendix 3).

Sociodemographic characteristics The sociodemographic characteristics of pwMS included items investigating age, gender, level of education, employment status, country, and duration of diagnosis.

Assessment of participation in research activities and in scientific writing This area was investigated using ad hoc items. Specifically, the questionnaire had two possible pathways: one for those who had already participated in research and/or scientific writing and another for those with no prior experience. The aim was to map, from their perspective, any strengths or barriers related to the research topic. Two yes/no questions were included to determine the percentage of people in different groups. Additionally, participants rated their agreement (on a scale from 1, not at all, to 7, very much) with specific statements designed to explore barriers (attitudinal, pragmatic, and emotional) towards research and scientific writing formulated from the previous phase. Four ad hoc items and one final open-ended question were included to capture additional motivation among participants. Thirteen more items, based on statements from the first phase, investigated attitudes towards scientific writing, with participants expressing their agreement on a scale from 1 (strongly disagree) to 7 (strongly agree). Lastly, participants rated the perceived importance (on a scale from 1, not at all, to 7, very much) of seven ad hoc items created based on the MULTI-ACT model [5], which describes different phases of engagement in the research process.

Patient engagement Patient healthcare engagement was evaluated using the validated Patient Health Engagement Scale (PHE-s®) [37]. The PHE-s® is a seven-item tool that allows patients to assess their healthcare engagement according to the Patient Health Engagement Model (PHE model), which identifies four consequent engagement phases from low to high: blackout, arousal, adhesion, and eudaimonic project. The PHE model [5] describes how patients emotionally and cognitively engage with their health and care management: *Blackout phase* – Patients experience emotional shock and psychological paralysis following a diagnosis or health crisis. They may feel overwhelmed, vulnerable, and unable to process information or make decisions about their health. *Arousal phase* – Patients begin to react emotionally to their condition, often feeling anxious, confused, and hypervigilant. They start seeking information but may struggle to manage conflicting emotions and health-related stress. *Adhesion phase* – Patients become more emotionally balanced and start to adhere to medical advice and treatments. They actively engage in managing their health but still rely heavily on healthcare providers for guidance and support. *Eudaimonic project phase* – Patients reach a stage of full engagement where they integrate their health condition into their identity. They feel empowered, take proactive steps in self-management, and collaborate effectively with healthcare professionals to maintain well-being. This scale was used in line with the premise of framing patient engagement in scientific writing as one of the possible roles they can assume within a perspective of greater awareness and proactivity in their care. The different levels of engagement were, in fact, used to understand whether this variable could somehow influence patients' attitudes toward the topics under investigation. This scale, with a single-factor ordinal structure, permits intermediate positioning and minimizes social desirability bias. In this study, PHE-s® scores were categorized into low and high engagement, using a cut-off of <3 and ≥ 3, respectively. The original scale exhibited good internal reliability (Ordinal $\alpha = 0.85$) [37], while the current study showed high internal consistency (Cronbach $\alpha = 0.86$).

Quality of life Participants' quality of life levels were measured with the SF-12 Health Survey [38], originally developed in the United States as a shorter alternative to the SF-36 [39]. The SF-12 consists of 12 items derived from the SF-3, providing two measures related to physical and mental health. The SF-12 includes four scales (physical functioning, role-physical, role-emotional, and mental health), each measured by two items, and four scales (bodily pain, vitality, social functioning, and general health), each measured by a single item. This scale was used in line with the premise of understanding how the quality of life of these patients, significantly impacted by progressive MS, could play a role in shaping their attitudes towards the topics under investigation. Participants respond based on their feelings and ability to perform usual activities, considering the day they complete the questionnaire and the preceding four weeks. The SF-12 scoring yields two summary measures, the physical and mental components, categorized as low and high, using a cut-off of <50 and ≥ 50, respectively.

Procedure

A letter explaining the project process and detailing its objectives preceded the survey. The MSIF shared it internationally through its media channels and the national MS societies that joined the project, using a snowball sampling technique.

Data analysis

The academic researchers involved in the participatory process conducted an initial analysis of the collected data. Statistical analyses were performed using IBM® SPSS 29 software (IBM Corp., Armonk, NY, USA). Descriptive statistics were reported as frequencies (percentages) for the categorical variables and as means (standard deviations) for the continuous variables. The normality of the data was assessed using the Shapiro-Wilk test, yielding a p-value >0.05, indicating that the data was normally distributed. Consequently, parametric tests were employed for subsequent data analysis. Specifically, the chi-square test was used to compare the participation in research activities/scientific publication initiatives regarding patients' age groups, gender, health engagement, and physical and mental quality of life levels. Additionally, an independent samples t-test was utilized to compare the ad-hoc items' scores to the health engagement and physical and mental quality of life levels of the participants. A p-value <0.05 was considered statistically significant.

Results

Results from the first phase of the participatory process – co-creation workshops

Results from the workshop discussions are reported here in terms of the topics that emerged and were consensualized among the participants. The first task focused on authorship equity, aiming to understand the beliefs underlying the concept of an author from lay perspectives and to identify barriers.

In the initial stages, the discussion aimed to outline the profile and characteristics that participants naturally attribute to an author of a scientific publication. In particular, for individuals affected by progressive MS, being considered an author of scientific publications primarily means being able to share their experience of the disease. This involves an awareness of possessing a unique, genuine experience marked by the challenges and difficulties

of the disease and being able to contribute concretely to problem-solving, as expressed by the participants:

> *…one who lives with MS who wants to share their experience and collaborate with others to find solutions.*

Furthermore, individuals with the disease who participate in the scientific writing process are those who engage in the entire process. They can describe, understand, and deeply discuss goals, phases, and processes, working collaboratively with researchers to define the project's course:

> *…Someone who participates in defining the project's direction (defining objectives, …).*
> *…who is involved in the entire research process.*
> *I believe the authors are those who are involved in research to discuss, describe whatever….*
> *For me, an author is simply one who lives a problem and wants to share the problem, trying to find with other people that have the same problem how to solve it.*

Participants highly value the opportunity for individuals with the disease to contribute with their ideas and words to the project:

> *…who contributes with ideas and wording.*
> *…try to better address on real needs and real lacks of pwMS….*
> *…contribute on plain language summary…" "… it's very important to have a plain language summary….*
> *Distinction between people who are involved in research projects and people who are clearly applicant authors, who are being involved at the very beginning….*

Additionally, group discussions revealed the spontaneous barriers and facilitators to involving people with progressive MS in scientific writing. These insights allowed for the categorization of barriers into several crucial levels: technical, psychological, institutional, and representational.

> *PwMS are involved only at the end of the process….*

At the technical level, participants identified perceived technical limitations related to language, cultural background, contribution structure, and editorial rules. Regarding language, the dominance of English was perceived as a barrier for non-native speakers, favoring individuals with advanced English skills and causing some to hesitate to participate due to feelings of inadequacy. Diverse cultural backgrounds could complicate communication and understanding among potential authors, potentially leading to confusion. To address these issues and promote inclusivity, it is imperative to conduct all phases of the research process leading to publication in multiple languages and using plain language. Clear communication goals should be established in advance, with support provided to overcome linguistic barriers.

> *…We have to come up with a new glossary….*
> *…the goal is to make the paper accessible to everyone, not destroy the scientific message.*
> *…explain in words that everyone can understand is an important part of scientific communication…it needs to be accessible to everyone….*

Another point pertains to the technical and organizational aspects of scientific contributions, specifically the rigid editorial formats required for publication. While these formats are recognized for ensuring the validity and comprehensibility of scientific contributions, individuals with progressive MS may perceive them as constraining and not always suitable for conveying their experiences or processing relevant information. To address this, individuals with progressive MS may benefit from working with more flexible, collaboratively created formats.

Another aspect highlighted in the group discussion is that the research and scientific publishing process can be lengthy and demanding for patients, requiring substantial cognitive investment. Patients with progressive MS often experience fatigue and may lack the time and energy for such activities. To address this, a support network should be established among individuals, with experienced individuals taking on guiding roles to simplify certain processes. Additionally, it is essential to offer more individualized activities, allowing people the time they need to fully participate.

As a result, individuals may feel out of their depth and may not even consider taking on roles in the scientific writing process. To overcome this barrier, the authorship group should establish clear and specific rules of engagement at the outset of the research process, including peer support and active listening. Additionally, the group should define the roles and contributions expected from each author based on their experience and willingness to participate.

Lastly, the group discussion revealed the need for expertise in RRI governance for engagement. This involves ensuring the "representativeness" of a wide range of experiential knowledge from people living with the disease and characterizing their level of engagement based on various factors, including education, economic, and social characteristics.

Following the above, as a final goal of the co-creation workshop, we defined a questionnaire to incorporate all the insights that emerged relating to the experience of being involved in research activities and in the co-authorship of a scientific paper and to enable a broader consensus process by involving other MS representatives.

Table 1 Descriptive characteristics of the participants ($n = 1120$)

Characteristics	*n* (%)	Mean ± SD
Age *(years)*		50.3 ± 13.18
Duration of diagnosis *(years)*		13.5 ± 10.40
Gender		
Female	825 (73.7)	
Male	288 (25.7)	
Other	1 (0.1)	
Prefer not to answer	6 (0.5)	
Level of education *(n = 898)*		
Less than a high school diploma	24 (2.1)	
High school diploma or equivalent	146 (13.0)	
Bachelor's degree	321 (28.7)	
Master's degree	166 (14.8)	
Post-doctorate	97 (8.7)	
Other	144 (12.9)	
Employment		
Employed full-time (40 + hours a week)	352 (31.4)	
Retired	338 (30.2)	
Employed part-time (less than 40 h a week)	155 (13.8)	
Unemployed (not currently looking for work)	154 (13.8)	
Self-employed	94 (8.4)	
Student	27 (2.4)	
Country		
Australia	44 (3.9)	
Austria	36 (3.2)	
Canada	149 (13.3)	
Italy	320 (28.5)	
New Zealand	69 (6.2)	
Spain	145 (12.8)	
United Kingdom	36 (3.6)	
United States of America	162 (14.3)	
Others	159 (14.2)	
Health engagement (PHE-s®)		
Low (Blackout, Arousal)	352 (31.4)	
High (Adhesion, Eudaimonic project)	768 (68.6)	
Physical QoL (SF-12)		
Low	1067 (95.3)	
High	53 (4.7)	
Mental QoL (SF-12)		
Low	635 (56.7)	
High	485 (43.3)	

SD, Standard deviation; *PHE-s®*, Patient Health Engagement Scale; *SF-12*, Health Survey Short Form

Results from the second phase of the participatory process: consensus survey

Descriptive characteristics of participants

Table 1 provides demographic and health-related characteristics of the study population, and the key findings include a mean age of 50.3 years (± 13.18), with a mean duration of diagnosis at 13.5 years (± 10.40). The majority of participants were female (73.7%), and the educational background of the participants varied, with the majority holding a bachelor's degree (28.7%), followed by those with a master's degree (14.8%). In terms of employment status, a significant proportion of the pwMS were retired (30.2%) or employed full-time (31.4%). The sample was primarily from Italy (28.5%) and the United States of America (14.3%). Health engagement was predominantly high (68.6%), while physical and mental QoL diversified, with a majority reporting low physical (95.3%) and a more balanced distribution for mental QoL (56.7% low, 43.3% high).

Comparison of participation in research initiatives regarding age, gender, health engagement and physical and mental QoL levels

Table 2 presents the participation in research initiatives and a comparison based on various demographic and health-related factors. A total of 613 participants (54.7%) reported having participated in research initiatives, while the others (45.3%) indicated no participation. Specifically, a higher proportion of pwMS aged ≥ 61 years old were more likely to participate in research initiatives (61.7% vs. 54.7%, $p < 0.05$), and individuals aged 18–39 years old were less likely to participate in research initiatives compared to the total sample (48.5% vs. 54.7%, $p < 0.05$). Individuals who reported having participated in research initiatives, with low health engagement were less likely to have participated in research initiatives (47.4% vs. 54.7%, $p < 0.05$), while patients with high health engagement were more likely to participate (58.1% vs. 54.7%, $p < 0.05$) compared to the total sample. Additionally, participants with high physical QoL reported less participation in research initiatives compared to the total sample (43.4% vs. 54.7%, respectively).

Comparison of elements encouraged participants to engage in research initiatives regarding health engagement and physical and mental QoL levels

Participants declare the willingness to be engaged in the whole seven phases process proposed by the MULTI-ACT model, feeling more confident to contribute those related to the beginning and end of the research process (e.g., (steering institutions, priority setting, communication) with the intermediate process of transforming data into results being entrusted to the scientists themselves) (Table 3). Table 4 shows the comparisons of elements that

Table 2 Comparisons of participation in research initiatives regarding their age, gender, health engagement, and physical and mental QoL levels ($n = 1120$)

	Yes *n* (%)	No *n* (%)
Have you ever participated in research initiatives?	613 (54.7)	507 (45.3)
Age *(years)*		
18–39 years old	**131 (48.5)***	**139 (51.5)***
40–60 years old	305 (54.2)	258 (45.8)
≥ 61 years old	**177 (61.7)***	**110 (38.3)***
Gender		
Female	444 (53.8)	381 (46.2)
Male	166 (57.6)	122 (42.4)
Health engagement (PHE-s®)		
Low (Blackout, Arousal)	**167 (47.4)***	**185 (52.6)***
High (Adhesion, Eudaimonic project)	**446 (58.1)***	**322 (41.9)***
Physical QoL (SF-12)		
Low	590 (55.3)	477 (44.7)
High	**23 (43.4)***	**30 (56.6)***
Mental QoL (SF-12)		
Low	333 (52.4)	302 (47.6)
High	280 (57.8)	205 (42.2)

Statistical significant results are highlighted in bold in the table

PHE-s®, Patient Health Engagement Scale; *SF-12*, Health Survey Short Form 12

x^2: *Pearson chi-square*

** Statistically significant at the p < 0.05 level compared to the total sample*

encourage pwMS to participate in research initiatives, with a focus on their health engagement and physical and mental QoL levels. Key findings include that pwMS with high health engagement reported significantly higher levels of feeling they possess the necessary skills to participate in research initiatives (t = -3.117, $p < 0.001$), expressed greater willingness to share their experience of living with MS (t = -2.064, $p = 0.020$), were more confident about the value of their lived experience (t = -2.028, $p = 0.022$), and reported having more time, energy, and/or resources (t = -3.283, $p < 0.001$) to participate in research initiatives compared to those with low health engagement. Also, pwMS with high mental QoL reported significantly higher levels of feeling they possess the necessary skills (t = -2.769, $p = 0.003$) and disclosed having more time, energy, and/or resources (t = -3.783, $p < 0.001$) to participate in research initiatives compared to those with low mental QoL. Finally, participants with high physical QoL demonstrated greater willingness to share their experience of living with MS compared to those with low physical QoL (t = -1.701, $p = 0.045$).

Comparison of participation in scientific publication initiatives regarding age, gender, health engagement, and physical and mental QoL levels

Table 5 illustrates the participation in scientific publication initiatives and compares based on various demographic and health-related factors. A total of 126 pwMS (11.3%) reported having participated as authors of scientific publications, while 994 patients (88.7%) indicated no participation. Although not shown in the table, 100 of the 126 participants who reported participation in previous scientific publications also reported participating in research activities. In particular, pwMS with high mental QoL had a significantly higher participation rate as authors in scientific publication initiatives compared to the total sample (14.0% vs. 11.3%, $p < 0.05$). No other statistically significant differences were observed for age, gender, health engagement, or physical quality of life.

Comparison of elements encouraged participants to engage in scientific publication initiatives regarding health engagement and physical and mental QoL levels

Table 6 displays comparisons of elements that encourage pwMS to participate as authors of scientific publications, with a focus on their health engagement and physical and mental quality of life levels. Participants with high health engagement were significantly more confident about the value of their lived experience (t = -3.876, $p < 0.001$) and reported having more time, energy, and/or resources (t = -3.216, $p < 0.001$) to participate in scientific publication initiatives compared to those with low health engagement. Additionally, participants with high physical QoL expressed greater willingness to share their experience of living with MS (t = -7.246, $p < 0.001$), were more confident about the value of their lived experience (t = -2.262, $p = 0.025$), and reported having more time, energy, and/or resources (t = -4.144, $p < 0.001$) to participate in research initiatives compared to those with low health engagement. No significant difference was found based on mental quality of life. Table 7 indicates the areas that patients report to be addressed to improve their engagement in scientific publications based on an ad-hoc item on the questionnaire.

Comparison of participants' attitudes toward participating in scientific publication initiatives regarding health engagement and physical and mental QoL levels

Table 8 compares participants' attitudes toward participating in scientific publication initiatives based on their health engagement and physical and mental QoL levels. Participants with high health engagement (t = -1.675, $p = 0.047$) and high mental QoL (t = -1.899, $p = 0.029$) reported a significantly higher level of agreement with having sufficient understanding of scientific terminology compared to those with low health engagement and

Table 3 Comparisons of participants' willingness to participate in seven phases of the MULTI-ACT model regarding their health engagement, and physical and mental QoL levels ($n = 1120$)

Phases of the MULTI-ACT model	Health engagement (PHE-s®)			Physical QoL (SF-12)			Mental QoL (SF-12)		
	Low	High	t; *p*	Low	High	t; *p*	Low	High	t; *p*
Breaking down barriers: to collaboration with researchers, clinicians and policy makers to review policies and clinical guidelines	6.1 ± 1.38	6.2 ± 1.21	-0.974; 0.165	6.1 ± 1.28	6.6 ± 0.81	-2.501; **0.006***	6.2 ± 1.25	6.1 ± 1.29	1.592; 0.056
Setting research priorities: to suggest priorities (e.g., give suggestions in specific research domains) for future research based on one's own illness experience	6.0 ± 1.31	6.1 ± 1.24	-1.119; 0.132	6.1 ± 1.26	6.1 ± 1.33	-0.187; 0.426	6.1 ± 1.26	6.0 ± 1.27	0.682; 0.248
Steering institutions: to express one's own worries and ethical concerns regarding research and clinical practices in order to improve them**	5.9 ± 1.39	5.9 ± 1.37	-0.211; 0.416	5.9 ± 1.36	6.1 ± 1.62	-0.527; 0299	6.0 ± 1.33	5.8 ± 1.43	2.320; **0.010***
Design & plan: to suggest specific objectives of research, expressing what really matters to patients in order to contribute to assessing the impact of scientific research on the real life of patients	6.1 ± 1.25	6.1 ± 1.22	-0.513; 0.304	6.1 ± 1.23	6.2 ± 1.23	-0.968; 0.167	6.1 ± 1.25	6.1 ± 1.21	0.007; 0.497
Research execution: to improve research execution by assisting in developing and monitoring research	5.6 ± 1.45	5.8 ± 1.41	-1.342; 0.090	5.8 ± 1.43	5.9 ± 1.32	-0.768; 0.221	5.7 ± 1.44	5.7 ± 1.41	0.050; 0.480
Evaluation: to evaluate if research impacts on outcomes (e.g., quality of life) matter most to patients	6.2 ± 1.09	6.3 ± 1.10	-0.673; 0.251	6.2 ± 1.11	6.5 ± 0.84	-1.583; 0.057	6.3 ± 1.08	6.2 ± 1.12	0.696; 0.243
Translation to the community: to help in translating scientific results in communication so that they are understandable for patients	6.0 ± 1.26	6.2 ± 1.37	-1.328; 0.092	6.1 ± 1.33	6.2 ± 1.51	-0.568; 0.285	6.1 ± 1.39	6.2 ± 1.27	-1.025_ 0.153

Statistical significant results are highlighted in bold in the table

PHE-s®, Patient Health Engagement Scale; *SF-12*, Short Form 12

t: Independent samples t test

** Statistically significant at the p < 0.05 level*

Table 4 Comparisons of elements encouraged participants to engage in research initiatives regarding their health engagement, and physical and mental QoL levels ($n = 613$)

Items / Variables	Health engagement (PHE-s®)			Physical QoL (SF-12)			Mental QoL (SF-12)		
	Low	High	t; *p*	Low	High	t; *p*	Low	High	t; *p*
I have the necessary skills	4.8 ± 2.05	5.3 ± 1.86	-3.117; **<0.001***	5.1 ± 1.93	5.3 ± 1.84	-0.332; 0.370	4.9 ± 2.02	5.4 ± 1.78	-2.769; **0.003***
I am willing to share my experience of living with MS	6.3 ± 1.20	6.5 ± 1.01	-2.064; **0.020***	6.4 ± 1.08	6.8 ± 0.67	-1.701; **0.045***	6.4 ± 1.12	6.5 ± 1.01	-1.462; 0.072
I am confident about the value of my lived experience for scientists	6.1 ± 1.23	6.3 ± 1.06	-2.028; **0.022***	6.2 ± 1.12	6.4 ± 0.94	-0.721; 0.236	6.2 ± 1.12	6.2 ± 1.08	0.254; 0.400
I have the time, energy and/or resources	5.2 ± 1.41	5.6 ± 1.30	-3.283; **<0.001***	5.5 ± 1.33	5.7 ± 1.62	-0.740; 0.459	5.3 ± 1.39	5.7 ± 1.24	-3.783; **<0.001***

Statistical significant results are highlighted in bold in the table

PHE-s®, Patient Health Engagement Scale; *SF-12*, Short Form 12

t: Independent samples t test

** Statistically significant at the p < 0.05 level*

mental QoL levels. Also, individuals with low health engagement (t = 2.223, $p = 0.013$) and low mental QoL (t = 1.957, $p = 0.025$) expressed feeling less free to tell their experience of living with the disease compared to those with high health engagement and mental QoL. In addition, participants with low health engagement (t = 1.858, $p = 0.032$) and low physical QoL (t = -2.711, $p = 0.003$) were significantly more likely to agree that the author of a scientific publication should have an academic background compared to those with high health engagement and physical QoL. Moreover, individuals with low mental QoL (t = 2.217, $p = 0.013$) were significantly more likely to agree that a person affected by MS has unique insight into what areas of investigation and research need to be prioritized and what questions need to be answered compared to those with high mental QoL levels. Participants with low health engagement (t = 1.781, $p = 0.038$) and low mental QoL (t = 3.620, $p < 0.001$) reported the

Table 5 Comparisons of participation in scientific publication initiatives regarding their age, gender, health engagement, and physical and mental QoL levels ($n = 1120$)

	Yes *n* (%)	No *n* (%)
Have you ever participated as an author of a scientific publication?	126 (11.3)	994 (88.7)
Age *(years)*		
18–39 years old	24 (9.0)	246 (91.0)
40–60 years old	64 (11.4)	499 (88.6)
≥ 61 years old	38 (13.2)	249 (86.8)
Gender		
Female	97 (11.8)	728 (88.2)
Male	29 (10.1)	259 (89.9)
Health engagement (PHE-s®)		
Low (Blackout, Arousal)	39 (11.1)	313 (88.9)
High (Adhesion, Eudaimonic project)	87 (11.3)	681 (88.7)
Physical QoL (SF-12)		
Low	119 (11.2)	948 (88.8)
High	7 (13.2)	46 (86.8)
Mental QoL (SF-12)		
Low	58 (9.1)	577 (90.9)
High	**68 (14.0)***	**417 (86.0)***

Statistical significant results are highlighted in bold in the table

PHE-s®, Patient Health Engagement Scale; *SF-12*, Short Form 12

x^2: *Pearson chi-square*

** Statistically significant at the p < 0.05 level compared to the total sample*

existence of many barriers for pwMS to be involved as authors of a scientific publication compared to those with high health engagement and mental QoL. Finally, individuals with lower physical QoL (t = -2.198, $p = 0.014$) and higher mental QoL (t = 2.341, $p = 0.010$) proclaimed that the scientific publication system creates barriers to authorship by non-scientists, compared to the other groups.

Table 7 Summary of key aspects of patient engagement in scientific publications identified by pwMS

Categories	Emerged key aspects
Support mechanisms	inclusive approach to the writing process, editorial support, translation support, access to resources, encouragement, receiving continuous feedback, guidance in scientific writing, online participation
Engagement needs	continuous contact with scientists, being part of the team, being invited to the research, collaboration with other patients, access to the research team, early involvement in the research, improved involvement, collaboration with other stakeholders
Barriers	Lack of financial support, not having more time, obstacles in English language skills, cancellation of personal experiences, lack of practical experience
Facilitators	having a scientific background, having research knowledge and skills, having a PhD, having previous research experiences, improved self-confidence, inclusion agreed in the writing process, ability to design research
Personal outcomes	feeling healthier, being recognized, improved self-confidence

The expectations and suggestions of people with MS for future research

The survey results also provide an overview of the gaps and barriers to the engagement of pwMS in the writing of scientific articles, as identified by the respondents themselves. At the same time, through the responses to question 9 in the survey, elements that could intensify and strengthen this engagement are identified (Table 7). The summary table identifies issues raised by people with MS, highlighting areas where improvement is needed. These areas include the provision of guidance in scientific writing, more meaningful contact with scientists, a more inclusive writing process, improved engagement in the early stages of a project, and assistance with both scientific and English language translation.

Table 6 Comparisons of elements encouraged participants to engage in scientific publication initiatives regarding their health engagement, and physical and mental QoL levels ($n = 126$)

Items / Variables	Health engagement (PHE-s®)			Physical QoL (SF-12)			Mental QoL (SF-12)		
	Low	High	t; *p*	Low	High	t; *p*	Low	High	t; *p*
I have the necessary skills	5.9 ± 1.48	6.0 ± 1.48	-0.179; 0.429	6.0 ± 1.42	5.6 ± 2.29	0.758; 0.225	5.9 ± 1.64	6.1 ± 1.33	-0.612; 0.271
I am willing to share my experience of living with MS	5.6 ± 1.69	6.1 ± 1.63	-1.572; 0.059	5.9 ± 1.69	7.0 ± 0.00	-7.246; **<0.001***	6.1 ± 1.64	5.8 ± 1.68	0.715; 0.238
I am confident about the value of my lived experience for scientists	5.3 ± 1.70	6.4 ± 1.19	-3.876; **<0.001***	6.0 ± 1.46	6.7 ± 0.75	-2.262; **0.025***	6.1 ± 1.43	6.0 ± 1.46	0.456; 0.325
I have the time, energy and/or resources	4.9 ± 1.26	5.7 ± 1.35	-3.216; **<0.001***	5.4 ± 1.37	6.7 ± 0.75	-4.144; **<0.001***	5.4 ± 1.38	5.6 ± 1.37	-0.717; 0.237

Statistical significant results are highlighted in bold in the table

PHE-s®, Patient Health Engagement Scale; *SF-12*, Short Form 12

t: Independent samples t test

** Statistically significant at the p < 0.05 level*

Table 8 Comparisons of participants' attitudes toward engaging in scientific publication initiatives regarding their health engagement, and physical and mental QoL levels ($n = 1120$)

Items / Variables	Health engagement (PHE-s®)			Physical QoL (SF-12)			Mental QoL (SF-12)		
	Low	High	t; *p*	Low	High	t; *p*	Low	High	t; *p*
I have sufficient understanding of scientific terminology to contribute to a scientific publication	3.9 ± 1.85	4.1 ± 1.84	-1.675; **0.047***	4.0 ± 1.84	4.2 ± 1.85	-0.722; 0.235	4.0 ± 1.83	4.1 ± 1.86	-1.899; **0.029***
I do not feel free to tell my experience of living with the disease if I need to fill in a precise format for publication	3.2 ± 1.67	2.9 ± 1.73	2.223; **0.013***	3.0 ± 1.70	2.9 ± 2.02	0.560; 0.288	3.1 ± 1.77	2.9 ± 1.64	1.957; **0.025***
I have the relevant scientific training and qualifications to contribute to a scientific publication	3.2 ± 2.01	3.2 ± 1.94	-0.079; 0.468	3.2 ± 1.96	3.3 ± 2.03	-0.593; 0.276	3.2 ± 1.95	3.2 ± 1.97	-0.038; 0.485
The author of a scientific publication should be involved in the entire research process	5.3 ± 1.48	5.3 ± 1.51	-0.270; 0.394	5.3 ± 1.49	5.2 ± 1.59	0.370; 0.356	5.3 ± 1.51	5.3 ± 1.48	-0.407; 0.342
The author of a scientific publication should have an academic background	5.4 ± 1.41	5.2 ± 1.59	1.858; **0.032***	5.2 ± 1.54	5.8 ± 1.34	-2.711; **0.003***	5.2 ± 1.55	5.3 ± 1.52	-0.953; 0.170
A person affected by MS has unique insight into what areas of investigation and research need to be prioritized and what questions need to be answered	5.6 ± 1.29	5.5 ± 1.42	1.212; 0.113	5.5 ± 1.37	5.7 ± 1.43	-0.876; 0.191	5.6 ± 1.37	5.4 ± 1.38	2.217; **0.013***
A person affected by MS could be the author of a scientific publication because he/she lives with the disease	4.8 ± 1.57	4.8 ± 1.63	-0.639; 0.262	4.8 ± 1.61	4.9 ± 1.66	-0.344; 0.366	4.8 ± 1.61	4.8 ± 1.60	0.301; 0.382
A person affected by MS could be the author of a scientific publication because he/she can express needs about the disease	5.1 ± 1.45	5.0 ± 1.45	0.233; 0.408	5.0 ± 1.45	5.3 ± 1.42	-1.317; 0.094	5.1 ± 148	5.0 ± 1.42	0.358; 0.360
The format of scientific publications is sufficiently flexible to accommodate contributions from lived experience experts	4.5 ± 1.47	4.6 ± 1.44	-1.175; 0.120	4.5 ± 1.45	4.8 ± 1.56	-1.145; 0.126	4.5 ± 1.49	4.6 ± 1.40	-1.004; 0.158
There are many barriers for people affected by MS to be involved as authors of a scientific publication	4.8 ± 1.34	4.6 ± 1.37	1.781; **0.038***	4.7 ± 1.36	4.9 ± 1.43	-1.037; 0.150	4.8 ± 1.38	4.5 ± 1.33	3.620; **<0.001***
I hope in the future the scientific system will become more inclusive	5.6 ± 1.18	5.6 ± 1.22	-0.012; 0.495	5.6 ± 1.20	5.8 ± 1.26	-1.139; 0.127	5.7 ± 1.21	5.6 ± 1.19	1.351; 0.088
The way the scientific publication system works does not currently accommodate/creates barriers to authorship by non-scientists	5.1 ± 1.31	5.0 ± 1.29	1.628; 0.052	5.0 ± 1.29	5.4 ± 1.33	-2.198; **0.014***	5.1 ± 1.32	4.9 ± 1.26	2.341; **0.010***

Statistical significant results are highlighted in bold in the table

PHE-s®, Patient Health Engagement Scale; *SF-12*, Short Form 12

t: Independent samples t test

** Statistically significant at the p < 0.05 level*

Discussion

The value of patient engagement in scientific writing is increasingly recognized, as patient authors influence a wide range of publication stakeholders globally, including patient advocates, academics, publication professionals, conference committees, journal editors, publishers, and funders (e.g., government, biopharmaceutical industry, charities) [35]. However, while the reasons for engaging patients in scientific publications are clear, there is still no consensus on how to achieve this goal and which are the main factors intervening in this process. One challenge is that there is no 'one size fits all' approach to publications. In this study, we applied the MULTI-ACT participatory model to evaluate patient experiential knowledge and input in defining the publication process. We also built on existing evidence-based best practice recommendations for engaging patients in scientific writing [35, 40]. It is important to highlight the unique value that patient contributions, based on their lived experiences, can bring to scientific publications from inception to completion; however, it is also essential to consider the practical and ethical challenges that may arise from this engagement process.

Our findings indicate a distinction between merely incorporating patient experiential knowledge and actively expanding patient engagement in scientific publications. Patients can play a crucial role in translating research findings into practical insights for the scientific community. To achieve this, it is essential to clearly define the scope of the article at the outset and align it with the target journal and readership that may ensure that both the scientific community and the public can benefit from the publication. Acknowledging the power of experiential knowledge as a legitimate form of evidence is also needed for a more holistic approach to research, one that values both scientific data and lived experience.

On the other side, it is also important that the research processes adapt to include them at every stage. This requires a fundamental shift in how scientific research is structured. This can be achieved by creating guidelines for patient engagement in scientific writing that are flexible and inclusive, providing patients with the necessary training and support, and recognizing the unique value they bring to the table. Furthermore, scientists should engage in reflexivity—critically examining their own biases and the traditional hierarchies in academia—to consciously create space for experiential knowledge within scientific discourse [41]. Investing in training programs for researchers on inclusive research practices and cultural competence can further support the integration of patient insights. This training can help scientists recognize and mitigate power imbalances, leading to more ethical and impactful research outcomes [42]. By making these deliberate efforts, scientists can create research environments that genuinely value and incorporate patients' experiential knowledge, leading to more comprehensive and socially relevant scientific contributions.

Ethically, it is important to highlight both the advantages and disadvantages for patients of participating in or being excluded from the publication process, as this transparency supports full and equitable engagement. Based on the above, it is crucial that patients are given the opportunity to decide how they would like to be involved in the publication process, thereby expanding their presence as authors and allowing them to make a meaningful impact [43]. It is also important for the scientific writing and publication system to review its policies and structures to better accommodate patient contributions. Currently, there is a risk of "self-selection bias" in the inclusion of patients in the research and scientific writing process, as these processes are often "top-down" and overly oriented by expert knowledge and scientific expertise [11]. To ensure inclusiveness and enhance diversity, the barrier posed by the exclusive use of the English language must be addressed, as it significantly deters participation. To overcome systemic barriers, particularly linguistic challenges, we recommend that the scientific writing and publication process be adapted to better support patient engagement. This includes providing access to translators or interpreters to address language fluency issues, thereby facilitating participation regardless of linguistic background. Implementing governance mechanisms, including actions by non-profit advocacy organizations, could help mitigate barriers that currently hinder the inclusiveness and true representativeness of the patient population while also involving a wider audience. Furthermore, emerging tools in artificial intelligence could play a significant role in alleviating these linguistic challenges, providing more accessible pathways for pwMS to contribute to scientific discourse.

The results of our survey indicate that pwMS are eager to contribute to the research process, believing their perspective and lived experience can significantly enhance its impact. They feel they possess the relevant skills, time, and energy needed for meaningful participation. However, the level of awareness about the disease and the perception of quality of life can influence patients' predisposition toward research and scientific writing. Patients may be at different stages of psychological engagement: some may be too psychologically burdened to participate, even though their needs and experiences are crucial for guiding future research and development in medicine [6]. For this reason, it is essential to offer psychological support to patients in order to elaborate the effort of participating in scientific writing. As our results show, quality of life also impacts patients' attitudes and willingness to participate in scientific publications. For this reason, scientists need to adjust the timing and methods of writing to accommodate the diverse needs of patients. Building a shared agenda where each patient can define their own space and level of engagement may ensure greater equity [44].

Finally, the survey results indicate that only a small portion of participants involved in research activities ultimately become co-authors of the resulting scientific publications. Our results suggest that evaluating the patient engagement experience itself may ensure the adequate representativeness of patients in the publication process. As previously described, literature evidence indicates that patients are rarely engaged as co-authors of scientific papers, and when they are, their contributions often remain disconnected from the publication process itself [1]. Publishing as a patient co-author introduces important ethical and practical considerations, particularly regarding privacy and potential personal or professional implications. Identifying as a "patient" and publicly disclosing a diagnosis such as MS may expose individuals to unintended consequences, including stigma, discrimination in professional environments, or emotional distress. To address these concerns, journals and research teams must implement clear policies that protect patient co-authors' privacy. For example, offering the option to contribute anonymously or under a pseudonym could protect individuals who are uncomfortable publicly disclosing their health status. In addition, developing flexible authorship models can allow patients to contribute meaningfully without compromising their privacy: journals may allow acknowledgment sections that highlight contributions without explicitly identifying individuals as patients. Alternatively, group authorship under a collective name could be used.

Today, there is much discussion about the value of science and how this knowledge should reach citizens, including patients. The scientific landscape is

characterized by defined rules and formats that determine the validity and quality of knowledge produced. For patients to participate effectively in knowledge production, governance and psychosocial requirements must be considered to identify what is truly impactful and relevant for both communities. Systemic change is needed to make patient engagement meaningful, accessible, and effective, ensuring the representativeness of the community and fostering an effective two-way dialogue between scientists and patients. People with MS, coauthors of this paper, clearly state their opinions on the factors necessary to enable various contributions to the publication process. Analysis of the evidence of this research suggests that new guidelines are needed to facilitate patients' engagement in article writing (guidelines for writing). These guidelines should define the role of people with medical conditions as co-authors, outline the steps to follow, specify the criteria for collaboration, and establish the value of this participation within the scientific community.

Although promising and offering valuable insights into the discussion on patient engagement in scientific writing, this study has several limitations related to both methodology and discussion. Specifically, the participatory methodology employed proved particularly effective in strengthening patient engagement. However, it is also demanding, requiring patients to engage in complex tasks and critical thinking during meetings and independently. Additionally, while the online format was necessary to accommodate geographically diverse participants, it may have hindered interaction and the balance of power among participants. Patients might have hidden certain difficulties behind the screen, feeling unempowered to pause the process or actively intervene. Moreover, despite involving an international population and recognizing the importance of cultural factors in shaping attitudes and engagement, the authors chose not to include findings related to these variables. Incorporating such data would have further complicated the article's focus, which primarily centered on engagement dimensions and quality of life. Future research should address these aspects by providing more detailed information on participants' demographic profiles and exploring how these variables may impact their engagement process. Similarly, this paper did not address issues related to patient compensation, as the patients involved in this study participated on a voluntary basis. Considering the significant effort required and the fact that patients often contribute to research and publication activities in their personal time, this is an important issue that should be carefully considered in future studies on this topic. Finally, the authors chose to use the concept of engagement as it aligns with the objectives of the study and aims to shed further light on a concept that is becoming increasingly promising in patient care. The goal was to understand the role that even less considered aspects, such as psychological factors, may have in this process, especially considering the significant impact these factors can have on patients' disease experiences. However, the engagement of pwMS in scientific writing, particularly in relation to these aspects, remains an underexplored area. This focus may have led to the selection of specific yet relevant domains in order to ensure coherence and clarity within the manuscript.

Conclusions

Implementing patient engagement in scientific writing calls for a review of existing authorship guidelines, such as those of the International Committee of Medical Journal Editors [25] and modified versions [26]. This is a call to action for all relevant stakeholders to develop a format for scientific publications that incorporates patients' perspectives and fosters inclusivity and representativeness [7]. The development of guidelines, such as an Authorship Agreement, could address the perceived need for a scientific background, which currently deters the participation of individuals with MS. These guidelines will clarify both the value and role of patients as co-authors, emphasizing that their contribution stems from sharing their experiential knowledge rather than specific scientific expertise, which has its own intrinsic value. This point is further reinforced by the expressed desire of pwMS to feel like integral members of the research team, which likely stems from the unmet need to be engaged in all phases of the research process from the earliest stages.

A research and scientific writing model that promotes early engagement of patients in all stages of the research process will build the confidence of patients and help both scientists and patients recognize that their lived experiences have scientific validity and value. Institutional changes enabling the adoption of RRI MULTI-ACT-like models in the research governance will train patients to acknowledge the value of new science (science with patient input) [30] and increase their confidence to have the scientific background to contribute. Journals and institutions should also be encouraged to recognize and celebrate experiential knowledge as distinct from, but equally valuable to, scientific knowledge. This would help foster a more inclusive approach to authorship that acknowledges different forms of expertise contributing to research outcomes. Furthermore, a more sensitive approach should be adopted in order to take into account the psycho-social conditions of pwMS and what may hinder their participation in research and in writing scientific publications in order to really guarantee equal access to all. Psychological support or better "psychologically wise" conditions should be guaranteed in the procedures and processes offered by scientists to pwMS to enhance their ease of participation and engagement.

We believe that the global adoption of these principles of behavior will go a long way toward addressing the gap between the engagement of pwMS in research activities and their participation as authors of scientific publications. We believe that the global adoption of the Alliance Principles of Patient Engagement in Research together with the MULTI-ACT scientific framework will go a long way towards addressing the gap between the engagement of pwMS in research activities and their participation as authors of scientific publications. According to our experience a multistakeholder participatory governance in patient engagement in health research helps to address the expected fundamental mismatch of values between the academic and patient and the other stakeholders sides [30], also in scientific writing. The development of a scientific paper should be part of the shared-research mission and agenda, defining from the beginning of a research study multimensional expected impacts for each stakeholders. This will create unambiguous opportunities for all authors to contribute sharing publication values toward also an improved future exploitation of the published research results. Within this framework patient participation in scientific writing should reflect their engagement in research projects or initiative developed in line with RRI principles [46]. As a consequence a dedicated patient engagement plan in scientific writing (dissemination) should be included in the research proposal and relevant resources allocated to provide patients with a specific training and tools to reduce systemic barriers.

Supplementary Information

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Supplementary Material 1

Supplementary Material 2

Supplementary Material 3

Supplementary Material 4

Supplementary Material 5

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Author contributions
M.S., P.Z. and G.G. wrote the main manuscript text, revised the paperD.U. data analysis, wrote and revised the paperF.M. wrote and revised the paperV.F., F.B. wrote the Plain Language Summary, revised the paperAll authors reviewed the manuscript.

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