

Multiple sclerosis clinical trials: how to encourage patient participation? Results from a patient study conducted by Carenity.com – a worldwide online patient community.

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Background and objective

- Multiple sclerosis (MS) clinical research is in a worldwide competition.
- Patient engagement is key to optimize medical research and increase participation rate.

Objective: Identify levers to improve patients' motivations to join a clinical trial and identify hindrances to their enrolment in order to better communicate and increase participation rate.

Methods

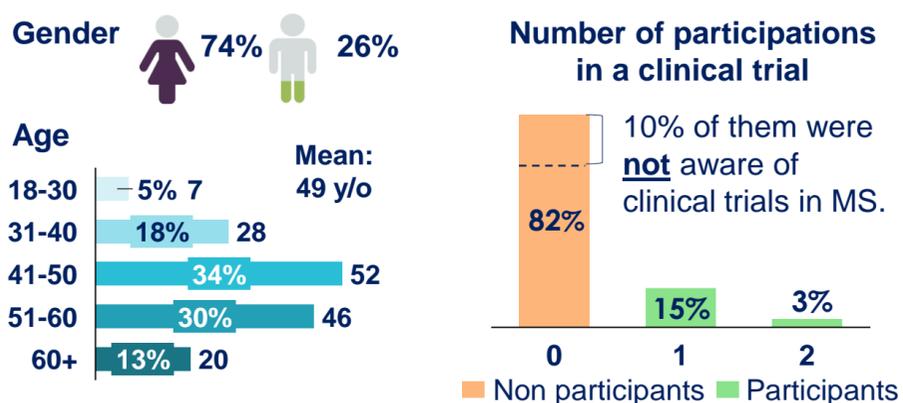
Carenity.com: an online patient community with 300,000 members in 6 countries (EU5 and USA) in which both patients and caregivers, affected by a chronic disease, can share their experiences, get informed, and contribute to medical research by participating in online studies.

The MS clinical trials online survey:

- ❖ **Inclusion criteria:** Adult member affected by MS, living in France and understanding what a clinical trial is.
- ❖ **Number of respondents:** 152 respondents within the inclusion criteria. 18% (n=27) have participated in a clinical trial.
- ❖ **Fieldwork duration:** August 2017 to October 2017.

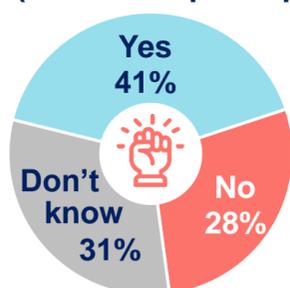
Results

Respondents' profile (n=152)



Non participants' motivations to join a trial

Willingness to participate in a trial (n=125 non participants)



41% of non participants are interested in participating in a clinical trial.

High potential for enrolment in MS clinical trial.

0=does not motivate patient to participate / 10=strongly motivates patients to participate	Mean score	p25	Med score	p75
Reimbursement of trial-related expenses	8.1	7	10	10
Possibility of curing my disease	7.8	6	9	10
Option to stop the trial in progress	7.3	5	8	10
Disease severity	7.2	5	8	10
Reputation of the doctor or service	6.6	5	7	9
Contribute to the advancement of science	6.6	4	7	9
Better medical follow-up	6.6	5	7	9
Reputation of the institution	6.5	5	7	9

Base: n=125 respondents who never participated in a trial

❖ **Reimbursement of the expenses related to the clinical trial is a key criteria** that motivates non participants to participate. **The possibility to stop the trial** in progress is also an important factor in which patients should be reassured. Finally, patients should understand that **they will have a better medical follow-up.**

Non participants' deterrents

0=no role in patient motivation to participate / 10=strongly deter patients to participate	Mean score	p25	Med score	p75
Potential side effects	7.7	6	8	10
Potential risk to my health	7.6	6	8	10
Negative opinion of my doctor	7.0	5	8	10
Risk of less effective treatment	6.9	5	7	10
Commute between home and trial site	6.8	5	7	10
Change in my site of care	6.2	4	6	9
Time to be assigned to a clinical trial	6.2	4	6	8
Change in my referring doctor	6.1	4	6	8

Base: n = 125 respondents who never participated in a trial

■ Easiest deterring factors to educate patients

💡 Communication should aim to reassure non participants about the potential side effects and risk for their health. Reassuring patients about changing their site of care should be done through solutions implemented to minimize constraints (eg: nurse coming home to realise analyses, mobile app to transmit results ...). Indeed, **1 out of 3 patients who have been invited to participate in a trial did not due to the travel time** between home and the healthcare centre.

Communication is a powerful trigger to improve participation

Tailored service and information

Non participant expectations for participating in a trial (n=125)

General information brochures on the trial	76%
Participant testimonials	75%
Brochures to help detect abnormalities	74%
Medical helpline	71%
Transportation service	69%

💡 While **only 30%** of participants had access to free transportation services, **the service would entice 7 out of 10** non participants to participate in a clinical trial. **Offering positive patient testimonials** through communications **addressed to specialists, GP, or clinical trial healthcare teams** appear also to be relevant.

Patients' favorite media to be invited in a trial

Online communities	76%
Healthcare websites	75%
Banners	74%
E-mail	71%

Conclusions

Concrete levers were identified to reassure patients affected with MS about the **benefits/constraints**. **Clarifying information** when inviting a patient to participate in a trial is essential to **accelerate recruitment**. **Facilitating access to information** through online patient communities or banners are also key. **Informing non participants about participants' experiences** would further help to improve the participation rate.