

# Rheumatoid arthritis and ankylosing spondylitis clinical trials: how to encourage patient participation? Results from a real-world study conducted via Carenity, a worldwide online patient community.

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## Background and objective

Involving patients affected with rheumatoid arthritis (RA) or ankylosing spondylitis (AS) in clinical trials may be highly challenging: in a worldwide context of competitive clinical research, patient engagement is key to optimize medical research and increase participation rates.

**Objective:** Identify patients' motivations for and hindrances to joining a trial in order to **increase participation rate** by implementing tailored services and information.

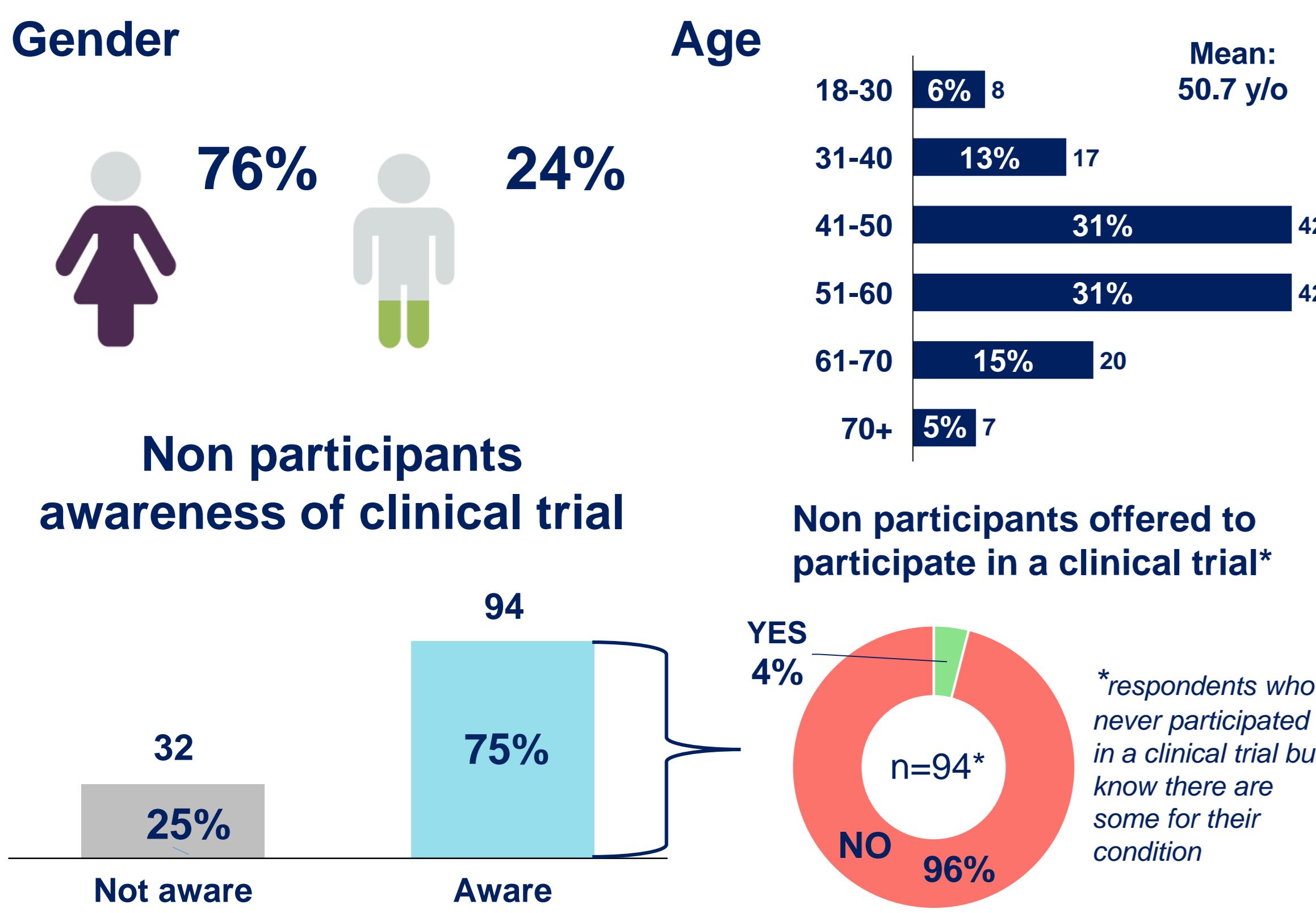
## Methods

Carenity.com is an **online patient community with more than 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 online survey:

- ❖ **Inclusion criteria:** Adult member affected by RA or AS, living in France and understanding what a clinical trial is.
- ❖ **Number of respondents:** 136 respondents within the inclusion criteria. 60% (n=81) have an AS and 40% (n=55) a RA. 7% (n=10) have participated in a clinical trial.
- ❖ **Fieldwork duration:** August 2017 to October 2017.

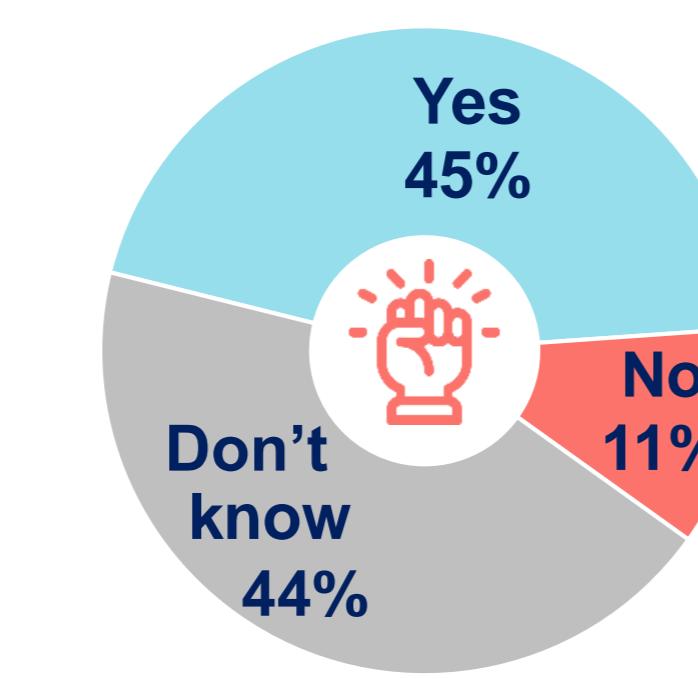
## Respondants' profile (n=136)



## Results

### Non participants' motivations to join a trial (n=126 non participants)

#### Willingness to participate in a trial



45% of non participants are interested in participating in a clinical trial

High potential for enrolment in clinical trial

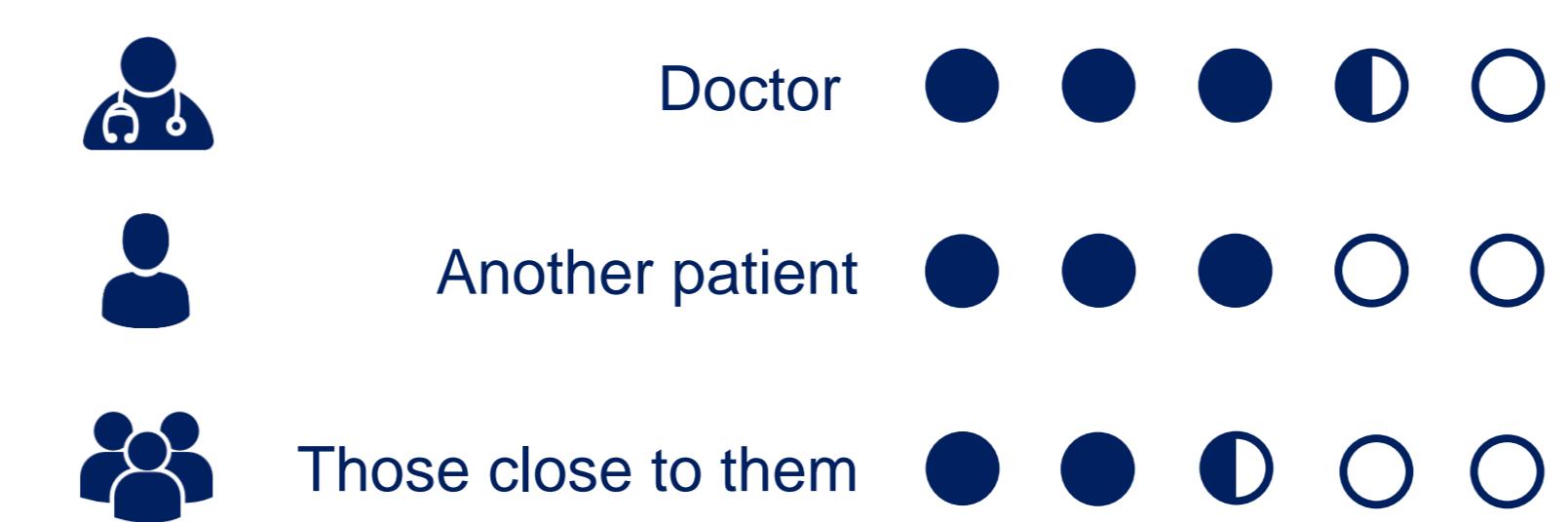
### Important aspects in patients' motivation

0 = does not motivate patients to participate / 10 = strongly motivates patients to participate	Mean score	p25	Med score	p75
Possibility of curing my disease	8.2	5	9	9
Reimbursement of trial-related expenses	8.1	7	10	10
Option to stop the trial in progress	7.6	6	9	10
Better medical follow-up	7.4	6	8	10
Disease severity	7.4	5	8	9
Reputation of the doctor or service	7.0	5	8	10
Contribute to the advancement of science	6.9	5	7	9

Easiest elements to better inform patients about clinical trials

💡 Several aspects should be highlighted during enrolment to motivate patients to join a trial. Patients want to be sure they will be **well reimbursed** the trial related expenses. The **possibility to stop the trial** in progress is also an important factor that remain unclear even for participants (5 out of the 10 participants were unclear on the conditions for leaving the clinical trial).

### Median mark affected to people's influence in the motivation to join a trial (n=126 non participants)



## Results

### Non participants' deterrents to join a trial (n=126 non participants)

0 = no role in patient motivation to participate / 10 = strongly deter patients to participate	Mean score	p25	Med score	p75
Potential side effects	8.1	7	9	10
Potential risk to my health	7.7	6	8	10
Negative opinion of my doctor	7.3	5	8	10
Risk of less effective treatment	6.8	5	8	10
Commute between home and trial site	6.7	5	8	10
Change in my referring doctor	6.7	5	7	9
Change in my site of care	6.5	5	7	9

Easiest elements on which patients can be reassured

💡 Although the potential side effects and risk for the health are the main non participants' deterrents to join a trial, communication should also reassure them about **logistical constraints**. **Solutions should be implemented and highlighted to minimize these constraints** (eg: nurse coming home to realise analyses, apps to transmit results...).

### Non participants' satisfaction about trials' information (n=70 non participants who have looked for information about trials)

0 = Not at all satisfied / 10 = Totally satisfied	Mean score	p25	Med score	p75
Terms and conditions for accessing clinical trials	3.0	0	2	5
Results of the past clinical trials	3.1	0	2	5
Existing clinical trials	3.1	1	2	5
Information after the clinical trial	3.2	1	3	5
General information	3.3	1	2	5
Medical follow-up during the clinical trial	3.6	1	3	5
Legislative aspect of clinical trials	3.7	1	3	6
Objective of clinical trials	3.8	1	4	5

Most important aspects to improve

💡 Patients are **not satisfied with the information** they receive about clinical trial. Communication around clinical trial should be **clearer and exhaustive** to convince patients to participate.

### Patients' favorite media to be invited in a trial (n=136)

Online communities	88%	120
Banners on websites	85%	116
Healthcare websites	85%	116
E-mail	65%	89

## Results

### Tailored service and information that would motivate non participants to join a trial (n=126 non participants)

Website to talk to healthcare professionals and/or to follow the results of the trial	81%	76
General information brochures on the course of the clinical trial	81%	76
Participant testimonials	79%	74
Brochures to help detecting abnormalities	78%	73
Information services by email	77%	72
Medical helpline	74%	70

💡 Tailored services and information should be implemented to increase patients' willingness to participate: through a direct access to healthcare professionals during the clinical trial via a website or a medical helpline; by spreading and clarifying information of the clinical trial process; by offering positive participants testimonials about their trial.

## Conclusions

**There is a high potential for RA and AS patients' enrolment in clinical trials.** 45% of non participants are interested in participating. Yet, only a small part of them actually participated.

**Concrete levers were identified to improve enrolment:**

- **Patients need to be reassured** about logistical constraints by implementing solutions to minimize them (nurse coming home, app...).
- They also **need to be encouraged** through communication about several aspects: reimbursement of trial-related expenses, option to stop the trial in progress, better medical follow-up...
- **Some tailored services and information are appreciated by patients** and should be implemented to motivate them. Eg. A website to talk to healthcare professionals and to follow the results of the trial.
- **Patients are generally not satisfied with the information** they receive about trials. It is important to provide them with **exhaustive and clear information**, in particular about **inclusion criteria**.