

# A Paradigm Change to Inform Fibromyalgia Research Priorities by Engaging Patients and Health Care Professionals

Fitzcharles et al. (2017)  
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## For which topic were research priorities identified?

fibromyalgia

## In which location was the research priority setting conducted?

North America - Canada

## Why was it conducted at all?

Research objectives should be focused toward advancing knowledge that has meaningful impact on health. However, research agendas are mostly driven by the health care community, with limited input from patients.

## What was the objective?

to engage patients, caregivers, and health care providers to identify the scope of uncertainties relating to the effects of treatments for adult fibromyalgia patients and to agree on a prioritized list of the top ten uncertainties that can be used by researchers and funding bodies to direct clinically meaningful research to improve the care of persons with fibromyalgia

## What was the outcome?

a ranking list of 10 research questions

## How long did the research prioritization take?

16 months

## Which methods were used to identify research priorities?

JLA method

## How were the priorities for research identified exactly?

Step 1: identifying uncertainties: survey: to collect research priorities, 4557 uncertainties submitted. Step 2: data processing: out-of-scope removed, grouped according to themes, duplicates combined, indicative questions developed, check against evidence, 43 questions remaining. Step 3: interim ranking: expert survey: experts rated the degree of impact of further research on how each of the 43 questions was currently answered by research and provided open-ended feedback and clarification, questions with low impact scores removed, resulting in shortlist of 25 questions. Step 4: final prioritization: workshop: small group discussions and rankings, group rankings were then combined, plenary discussion on final ranking

## Which stakeholders took part?

Patients, caregivers, clinicians and organization members. Survey: 550 participants: 292 patients and 109 clinicians. Interim ranking: steering group consisting of 5 patients and 5 clinicians. Workshop: steering group consisting of 5 patients and 5 clinicians and other patients and clinicians.

## How were stakeholders recruited?

A total of 109 groups/organizations/bodies were contacted as well as the original 139 voting participants in the Canadian 2012 Fibromyalgia Guidelines. The survey was distributed via partner organizations, societies, and social media.

## Were stakeholders actively involved or did they just participate?

Stakeholders not only participated but were also actively involved in the research prioritization process: They were part of a steering group. The steering group consisted of 12 members: 5 patients with FM, 5 health care professionals experienced in treating persons with FM (one family physician, two rheumatologists, one psychologist, one internist), an internist and the scientific director of IMHA. The members met by telephone conferences on 15 occasions over a 16-month period, developed survey questions and participated in the workshop.