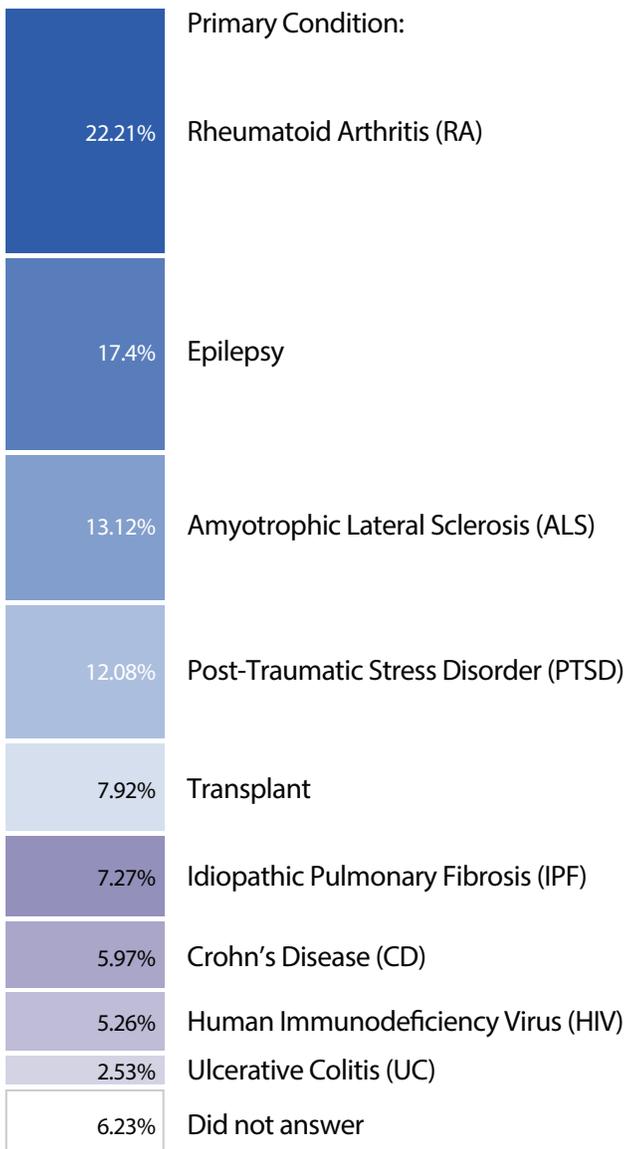


The Perceived Medical Condition Self-Management Scale

All through November 2013, more than 1,500 of you from 9 different PatientsLikeMe communities participated in an Open Research Exchange (ORE) questionnaire. You worked with our research partner Ken Wallston from Vanderbilt University to improve a health measure called the Perceived Medical Condition Self-Management Scale (PMCSMS). All of your answers and the feedback you gave helped make the health measure the best it can be, so thank you! This is your data doing good.

Which communities took part?

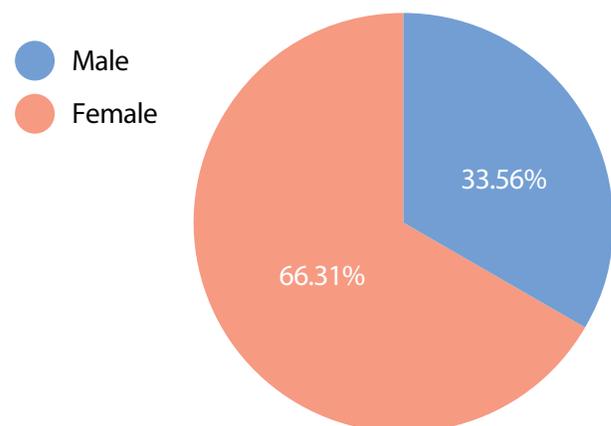


About health measures and the Perceived Medical Condition Self-Management Scale

Health measures and patient reported outcomes (PROs) are tools that researchers use to get a better understanding of your experiences with a condition and assess quality of life in ways that matter to you. The PMCSMS is a tool that measures how confident you are in managing your own condition.

Why use ORE? PatientsLikeMe's ORE platform gives you - the patient - the chance to not only check an answer box, but also share your feedback on each question in a researcher's health measure. You can tell our research partners what makes sense, what doesn't, and how relevant the overall tool is to your condition. It's all about collaborating with you as partners to create the most effective tools for measuring disease.

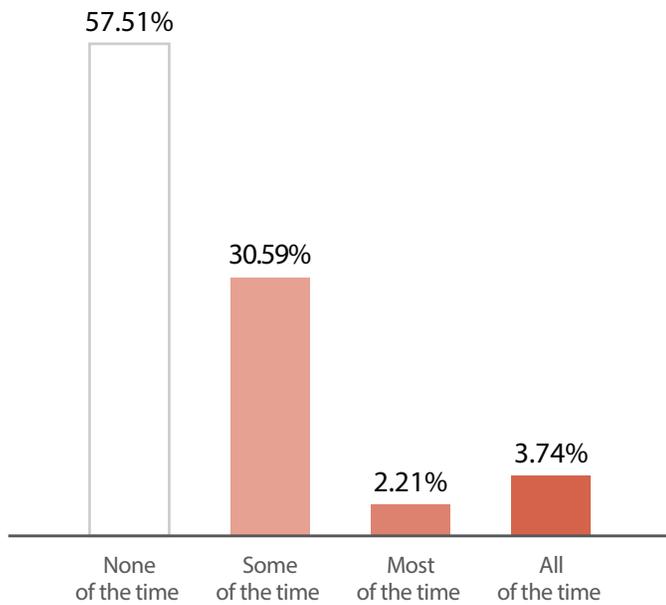
What was the gender breakdown?



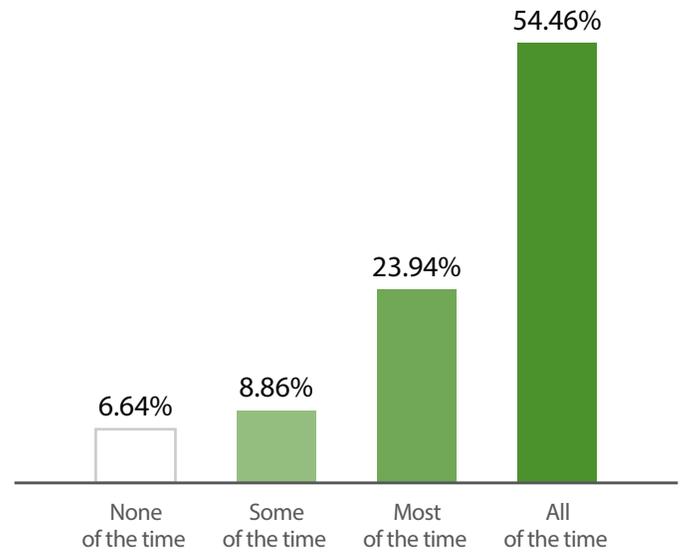
Uncovering how members manage conditions

The first part of the questionnaire asked about how you manage day-to-day living and how important self-management is to you. Here are some highlights:

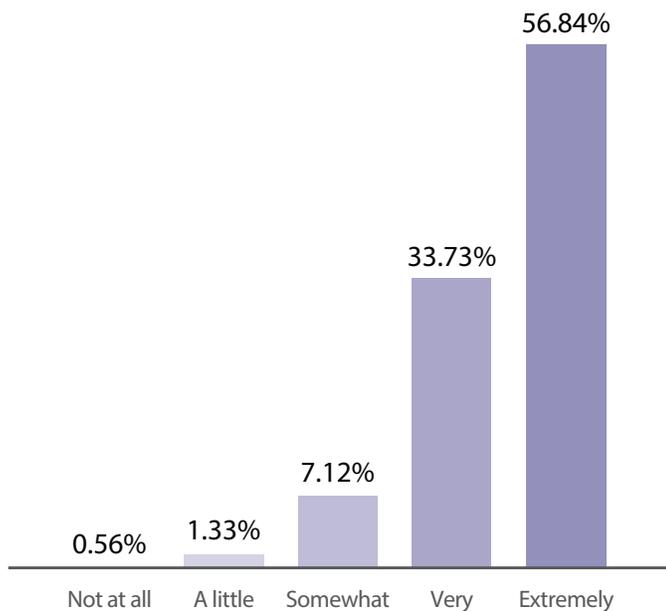
How often do you forget to take your medicine for this condition?



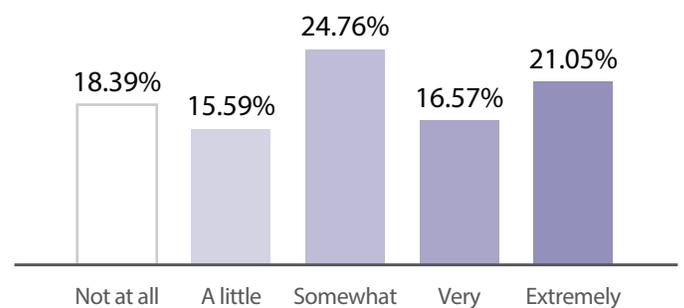
How often do you plan ahead and refill your medicines for this condition before they run out?



How important is self-management to you and your overall health?



How often does your health care provider discuss self-management of your condition with you?



In your own words

At the end of the questionnaire, Ken asked two open-ended questions to get a better idea of what self-management means for you and your condition. Almost everyone answered both questions, totaling more than 2,500 responses! Here's just a snapshot of how different communities answered:

What does the term 'self-management' mean in the context of your medical condition?



"Taking the steps needed to make the condition better or seeking help with the things you cannot do to manage your condition"
- Member with PTSD

"Taking the primary role in owning and overseeing the care for my condition"
- Member with CD

"I am my own medical advocate and I manage my medical team"
- Member with IPF

"To me, being given the information to direct my care, therefore knowing when to seek further care in relation to my degenerating condition" - Member with ALS



"It means that not only do I do what my doctors recommend, but also I'm pro-active and feel comfortable questioning them"
- Member post transplant

"I live by it. I have control of my health decisions"
- Member with HIV



"Having a good medical team willing to listen and honestly answer my questions no matter what"
- Member with RA

"Understanding my condition, knowing what my triggers are, learning more about my condition, seeking information about issues I'm having from my doctors and/or others with my condition. It also means that I know my body better than anyone else, and I know when something is wrong or changes"
- Member with epilepsy



"To me it means being able to manage my disease by eating right, exercise, and taking time out for yourself"
- Member with ulcerative colitis

Other than taking your medication and keeping your appointments, what other things do you do to self-manage your condition?

“Make sure I know where local toilets are and feel comfortable with the people I am around”
- Member with CD

“Helping others Working in the yard... Being outside”
- Member with HIV

“Agressively pursue pulmonary rehab and push myself on the equipment, take yoga and pace myself”
- Member with IPF

“Keeping to a healthy, well balanced diet & walking in the fresh air everyday”
- Member with ulcerative colitis

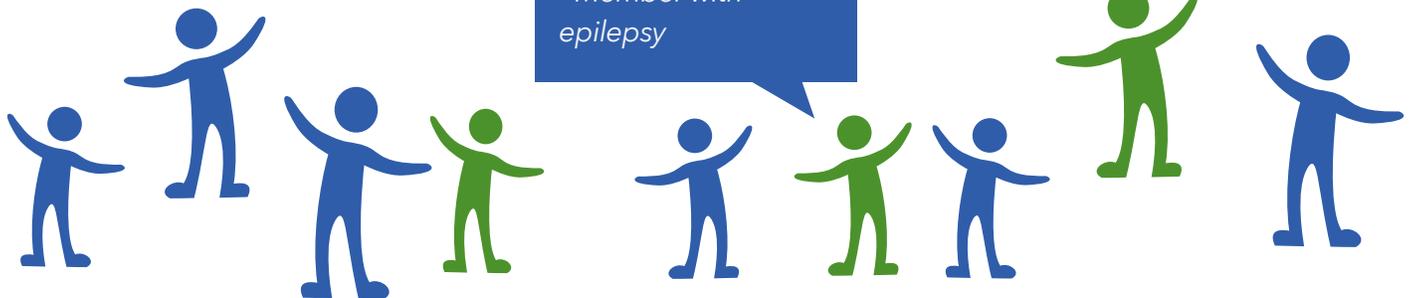
“ I think I do this by trying to stay connected with the organizations dedicated to finding the cause(s) and cure for ALS, trying to stay informed, and asking for help and guidance when I need it”
- Member with ALS

“I pay attention to feedback from my body—especially diet, exercise and sleep”
- Member with RA

“Creative arts are vital to my mental health. I also volunteer at an animal rescue centre”
- Member with PTSD

“Volunteer at the local elementary school. This helps me maintain a positive image of myself”
- Member with epilepsy

“Keep my mind and body as active and busy as possible”
- Member post transplant



More about PatientsLikeMe’s Open Research Exchange

With support from the Robert Wood Johnson Foundation, PatientsLikeMe launched the Open Research Exchange (ORE) in 2013 so that researchers, clinicians, academics and patients can collaborate to put patients at the center of the clinical research process. ORE is the hub where we can work together to develop new health outcome measures and increase our collective understanding of disease – faster than ever before.