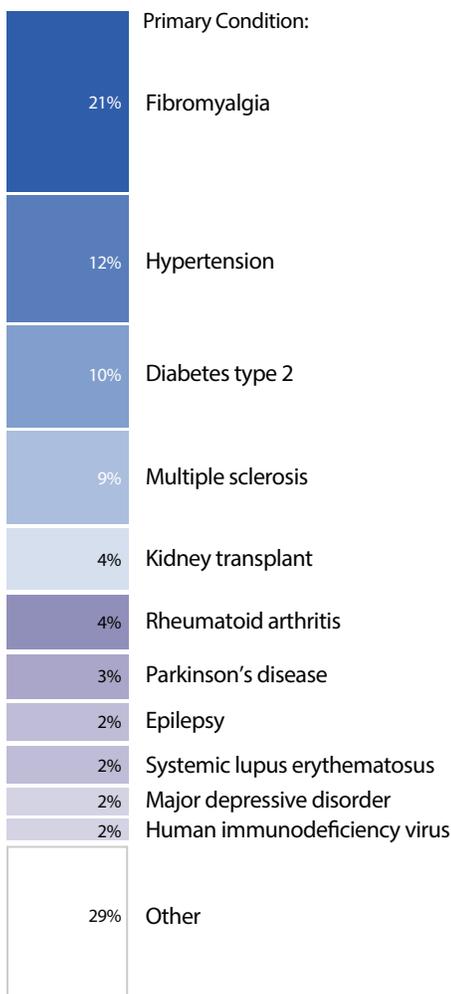


High Blood Pressure Management, Adherence, Attitudes and Health Behavior Instrument

Last fall, close to 500 of you who are living with hypertension took part in an Open Research Exchange (ORE) questionnaire. You worked with our research partner Tamara Kear, Ph.D. R.N., CNS, CNN from Villanova University to improve a health measure called the High Blood Pressure Management, Adherence, Attitudes and Health Behavior Instrument. (Wow! That’s a mouthful.) Thank you to everyone who took part! This is your data, and your feedback, doing good.

Which communities took part?

Many of you list hypertension as a condition on PatientsLikeMe, even if it’s not your primary diagnosis.

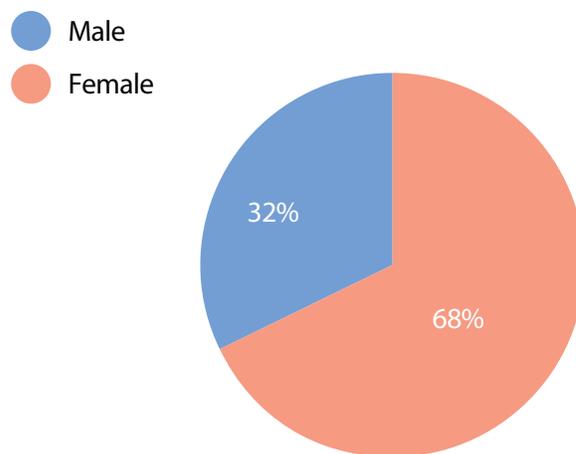


About health measures and the High Blood Pressure Management, Adherence, Attitudes and Health Behavior Instrument

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. Tamara’s measure can help patients like you and your practitioners work better together to get blood pressure under control as a team.

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?

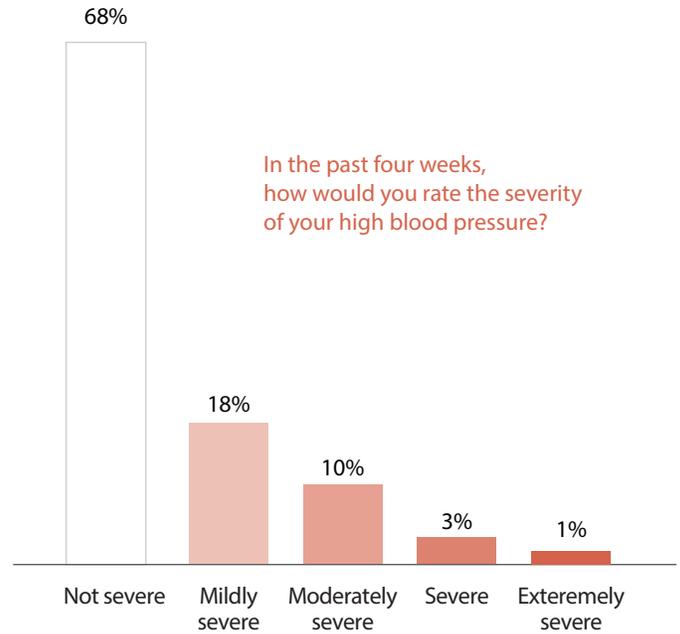




A note from Tamara

“High blood pressure is known as the ‘silent killer’ because most people living with this chronic condition do not have symptoms. Uncontrolled high blood pressure increases a person’s risk for stroke, cardiovascular disease, aneurysms and kidney failure. Some of you asked us ‘What are the symptoms of high blood pressure?’ and ‘I am not sure what the symptoms of high blood pressure might be.’

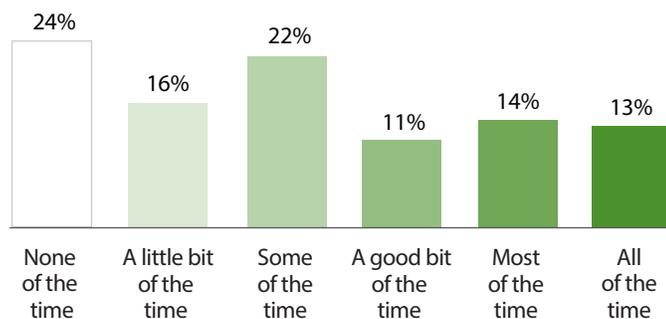
So let’s answer that question. Symptoms of high blood pressure often do not occur until the blood pressure is dangerously high and complications have started to occur. Such symptoms may include severe headaches, blurry vision, fatigue, nose bleeding, dizziness, seizures and facial flushing. These conditions require prompt medical care.”



Working with your health team to manage high blood pressure

Over 93% of you reported that when your health team checked your blood pressure during an office visit, they shared the results with you. Some of you had to ask for the data and others said you did not have to ask. Almost everyone (94%) felt it was important to know this reading from the doctor’s office visit. Here’s what you told us about working with your doctor and nurse:

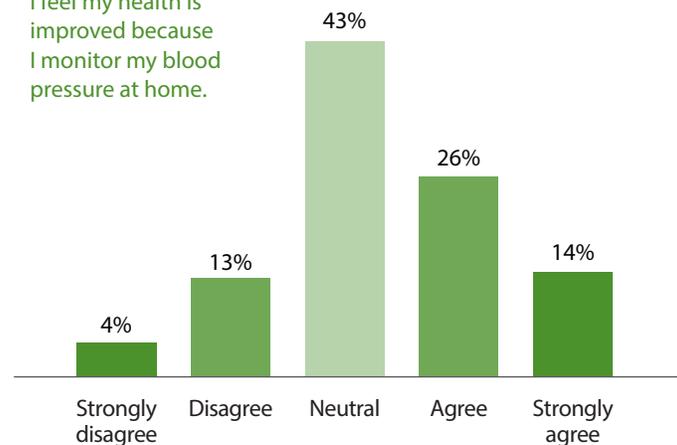
My health team provides info that helps me manage my blood pressure at home.



Managing high blood pressure at home

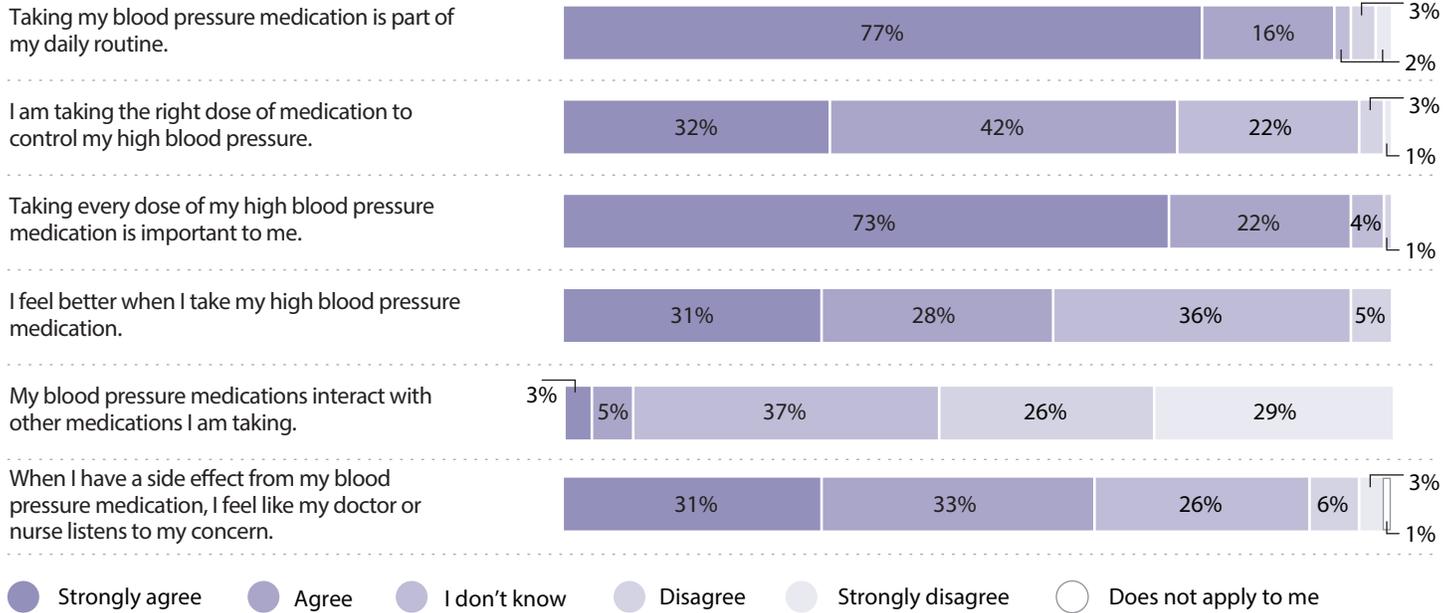
Several questions focused on the way you manage blood pressure at home. Over 61% of you monitor your blood pressure at home and nearly 40% record the home reading in a logbook or on your smartphone. You also revealed monitoring your blood pressure at home had health benefits:

I feel my health is improved because I monitor my blood pressure at home.



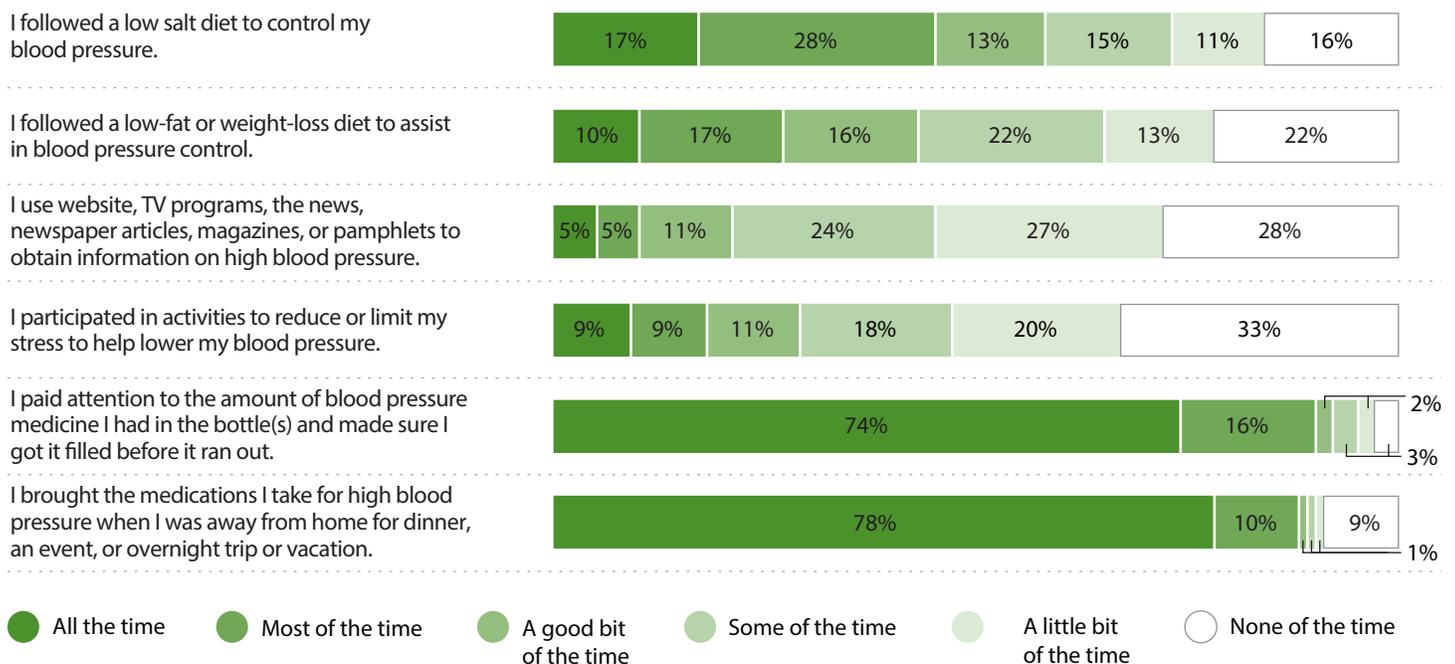
Taking high blood pressure medication

95% of you reported taking a medication to help control your high blood pressure. And many questions in the survey focused on adherence (i.e., if you take your medication as prescribed). Here's what you helped uncover:



Health behaviors and high blood pressure

The questionnaire also asked about health behaviors that can impact high blood pressure. They might include taking the prescribed medications, controlling your stress, limiting your intake of salty foods and alcohol, and not smoking. Here's what we found:



White coat syndrome is real

Wait. What is that? White coat syndrome happens when people have higher than normal blood pressure in a clinic or doctor's office setting compared to their home. You told us it exists in your own words!

The infographic features a central circular photo of a woman in a white lab coat. Surrounding this photo are four speech bubbles containing patient testimonials. A central rectangular box contains a summary message. The testimonials are: 1. Top-left (green stick figure): "My blood pressure was quite high in the office but not at home." 2. Top-right (blue stick figure): "I have anxiety in the waiting room...that increases my blood pressure." 3. Bottom-left (blue stick figure): "My blood pressure is always higher at the doctor's office because I get really stressed." 4. Bottom-right (green stick figure): "I have been diagnosed with white coat syndrome. I wore a monitor for 24 hours and it was regular." The central message box reads: "Knowing this, it's worth monitoring your blood pressure results at home and sharing what you discover with your health team. It is important to remember hard work, good communication and positive health behavior choices will be beneficial as you manage this common chronic condition. And know that you're not alone. High blood pressure impacts 30-40% of the global population."

"My blood pressure was quite high in the office but not at home."

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"Knowing this, it's worth monitoring your blood pressure results at home and sharing what you discover with your health team. It is important to remember hard work, good communication and positive health behavior choices will be beneficial as you manage this common chronic condition. And know that you're not alone. High blood pressure impacts 30-40% of the global population."

"My blood pressure is always higher at the doctor's office because I get really stressed."

"I have been diagnosed with white coat syndrome. I wore a monitor for 24 hours and it was regular."

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.