

Patient Reported Impact of Pulmonary Arterial Hypertension and Desired Treatment Outcomes

Authors: Dianna Cronin (MyHealthTeam), Elizabeth Luce (MyHealthTeam), and Beth Schneider (MyHealthTeam)

CONCLUSIONS

Understanding the physical, emotional, and quality of life impact of pulmonary arterial hypertension (PAH) can help doctors provide a more holistic approach to treating their patients. Importantly, by addressing the mental health aspects of PAH, listening to concerns and hopes for treatment, and encouraging patients to develop a support system for this daunting diagnosis, HCPs can help foster better health outcomes.

BACKGROUND

Patients diagnosed with the rare disease of PAH must deal not only with the physical aspects of PAH, but also the mental health, social, and economic ramifications of this life-changing disease. Understanding the holistic impact of PAH on patients along with patient needs is crucial to enabling them to live more fulfilling lives.

METHOD

In April 2024, an email invitation to an online survey was sent to US members of myPHteam. In total, 113 members diagnosed with PAH completed the 26-question survey.

RESULTS

The far-reaching impact of PAH was evident in the study. Most (88%) find it hard to be physically active, 83% feel it has negatively impacted overall quality of life and 53% feel it has impacted work, including no longer being able to work. (Figure 1)



The emotional impact of this progressive and devastating diagnosis was also pervasive, including experiencing anxiety (73%) or depression (62%). (Figure 2)

The large majority of PAH patients are experiencing a range of troubling symptoms, including fatigue (88%), shortness of breath (85%), and edema (58%). (Figure 3)

When asked to indicate their top five desired goals for treatment, results were consistent with symptom prevalence, including lessening fatigue (50%), being able to walk farther (50%), and making it easier to breathe (40%). The large majority (73%) hoped a treatment would stop further progression and 57% wanted a better quality of life. (Figure 4)

Almost all are on one or more treatments (92%), with 77% of these patients relying on multiple medications. (Figure 5)

Yet less than half feel their treatment regimen is effective (44%) as many still struggle daily. (Figure 6)

PAH patients are more likely to feel their regimen is effective if it helps make it easier to breathe (73% versus 36% among those finding their regimen to be ineffective), slows progression (56% versus 34%), is helping to prolong life (56% versus 32%) or makes it easier to live a full life (40% versus 7%). (Figure 7)

When asked why patients opted to join a health community for people with PAH, 52% were primarily interested in reading medically reviewed articles or watching videos and the remaining 48% were looking for support and tips or advice from others going through the same challenges of living with PAH. (Figure 8)

FIGURE 1. Impact of PAH on Quality of Life

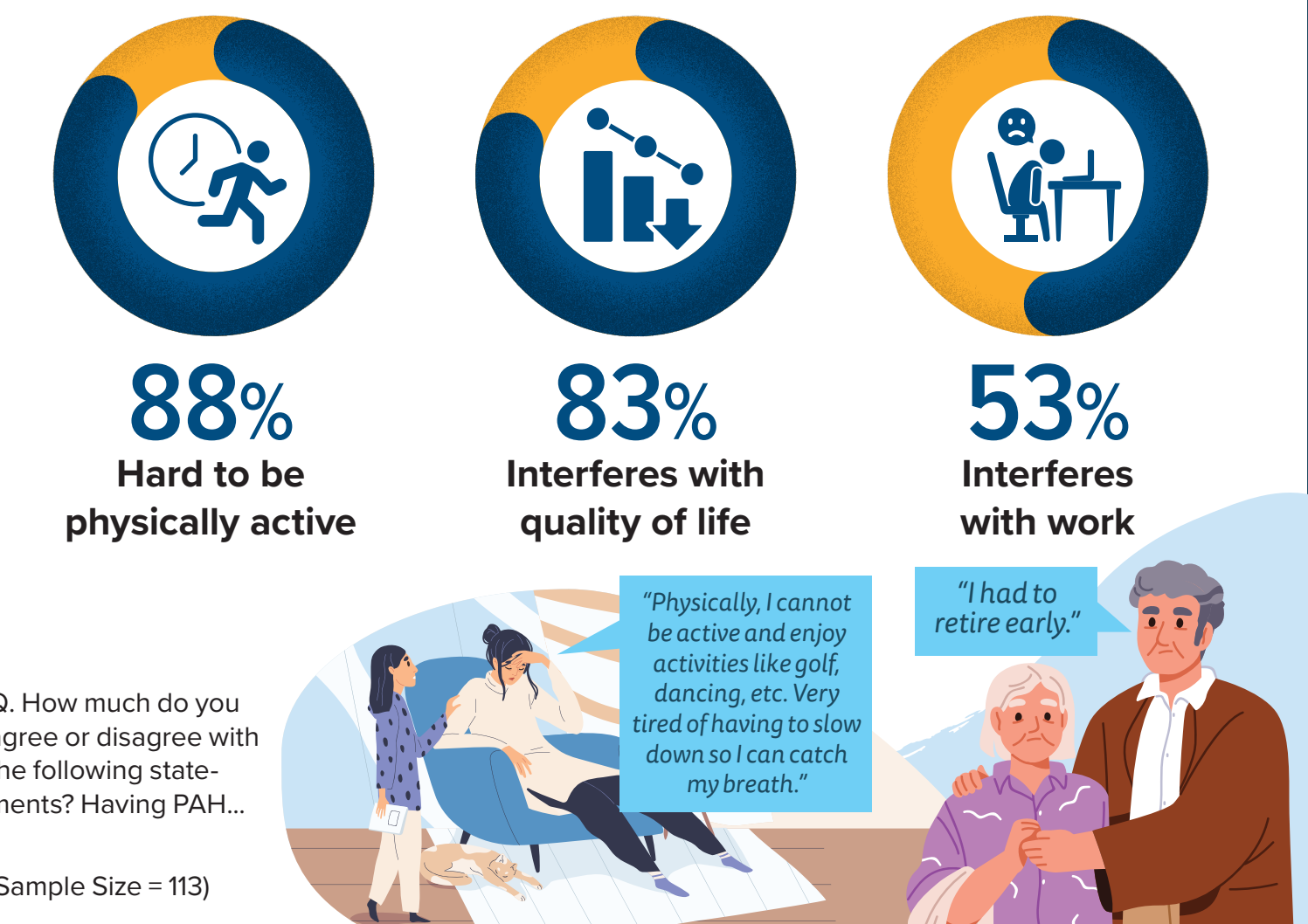


FIGURE 2. Impact of PAH on Mental Health

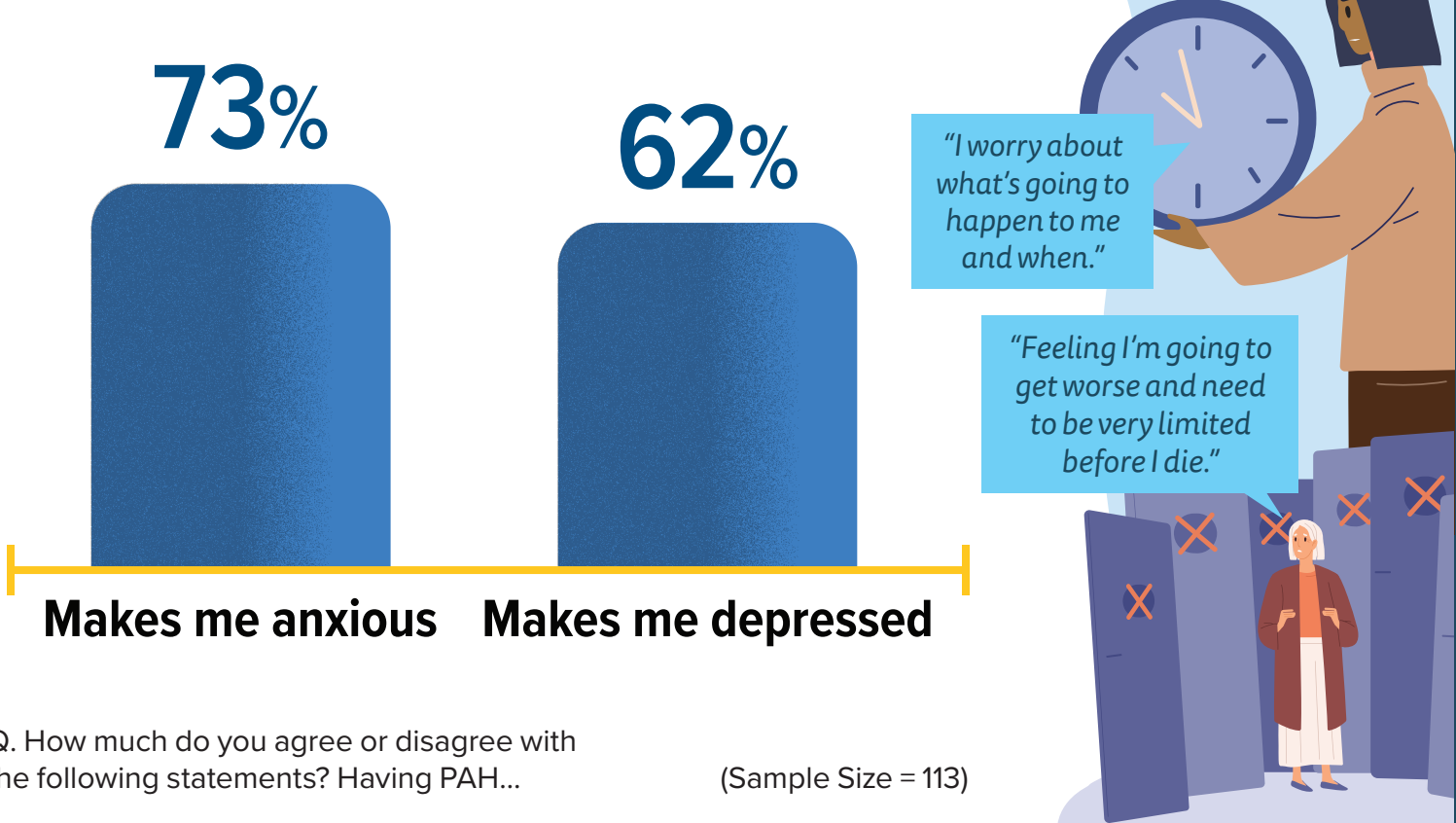


FIGURE 3. Symptoms Experienced Past Year

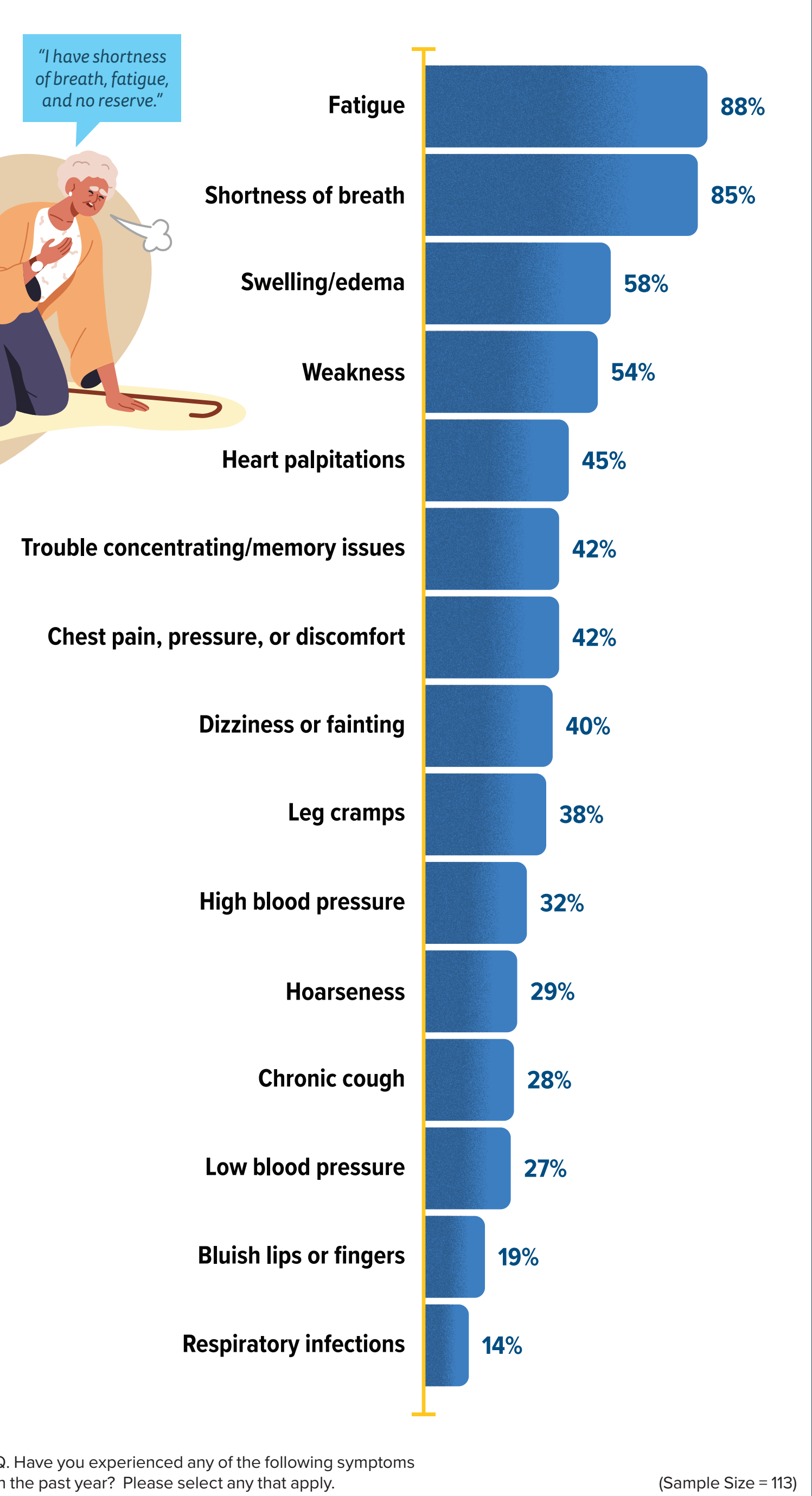


FIGURE 4. Desired Treatment Outcomes

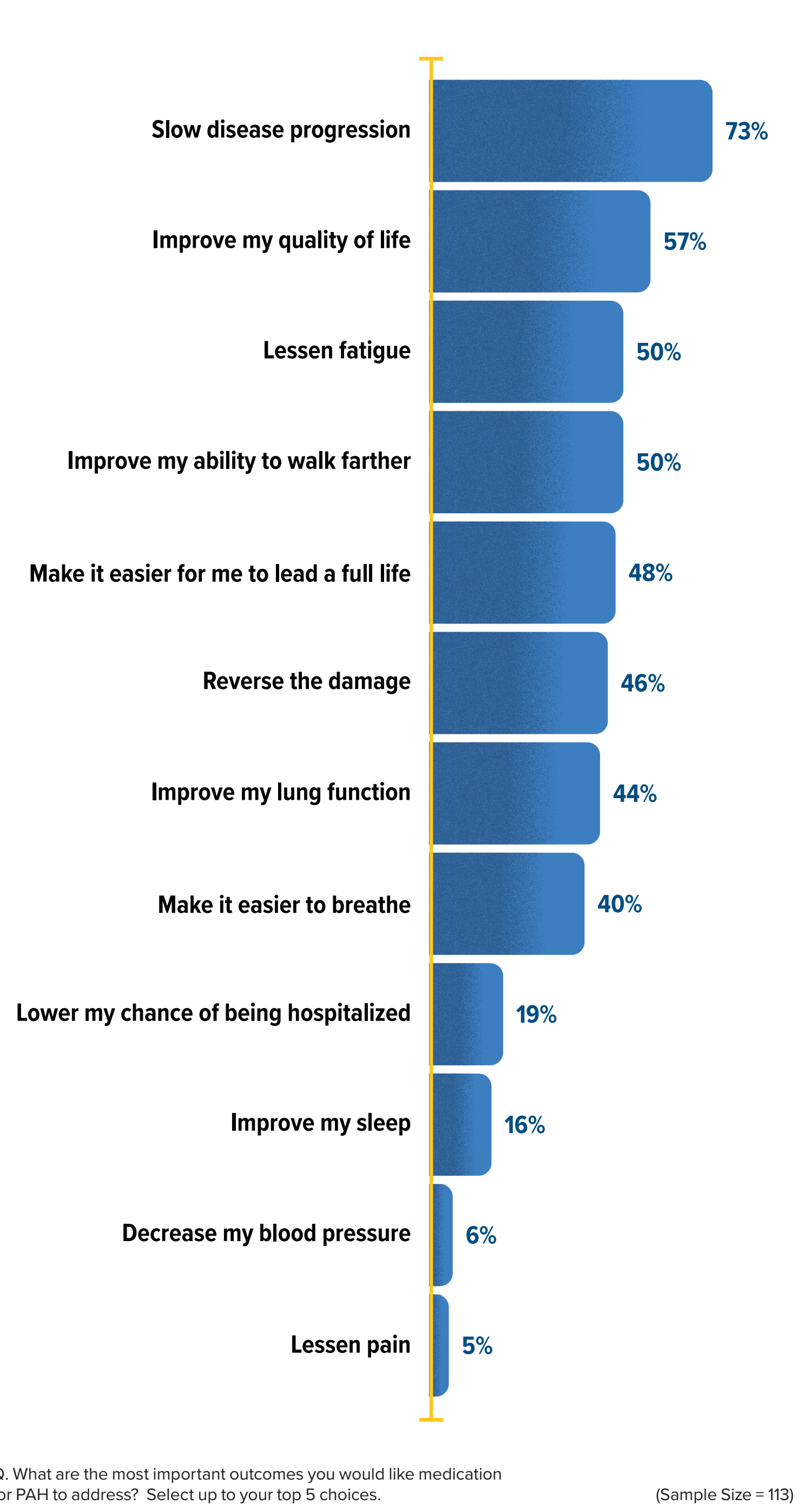


FIGURE 5. How Many Different Medications Taking (Among the 92% Taking Medication for PAH)

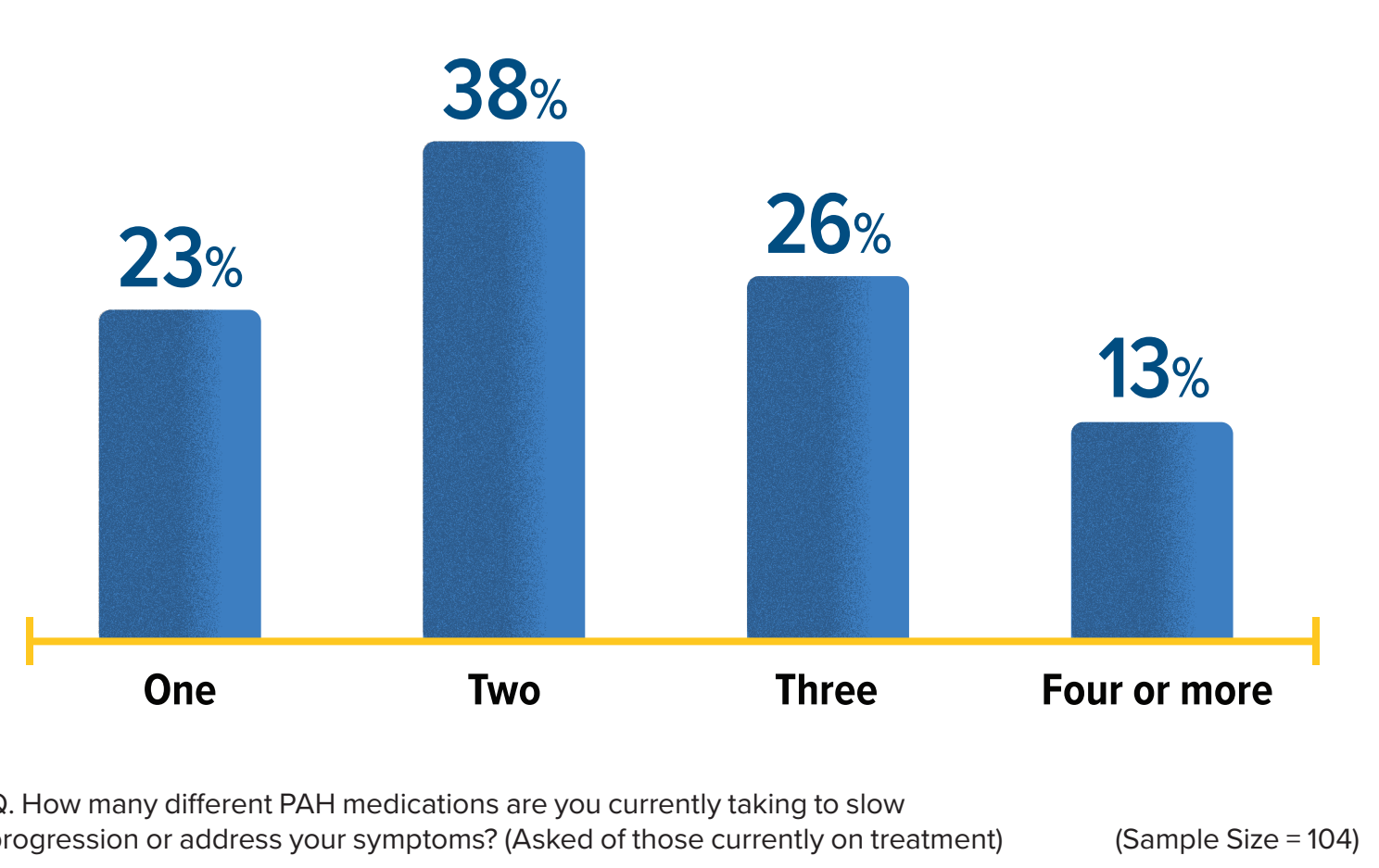


FIGURE 6. Treatment Regimen Effectiveness

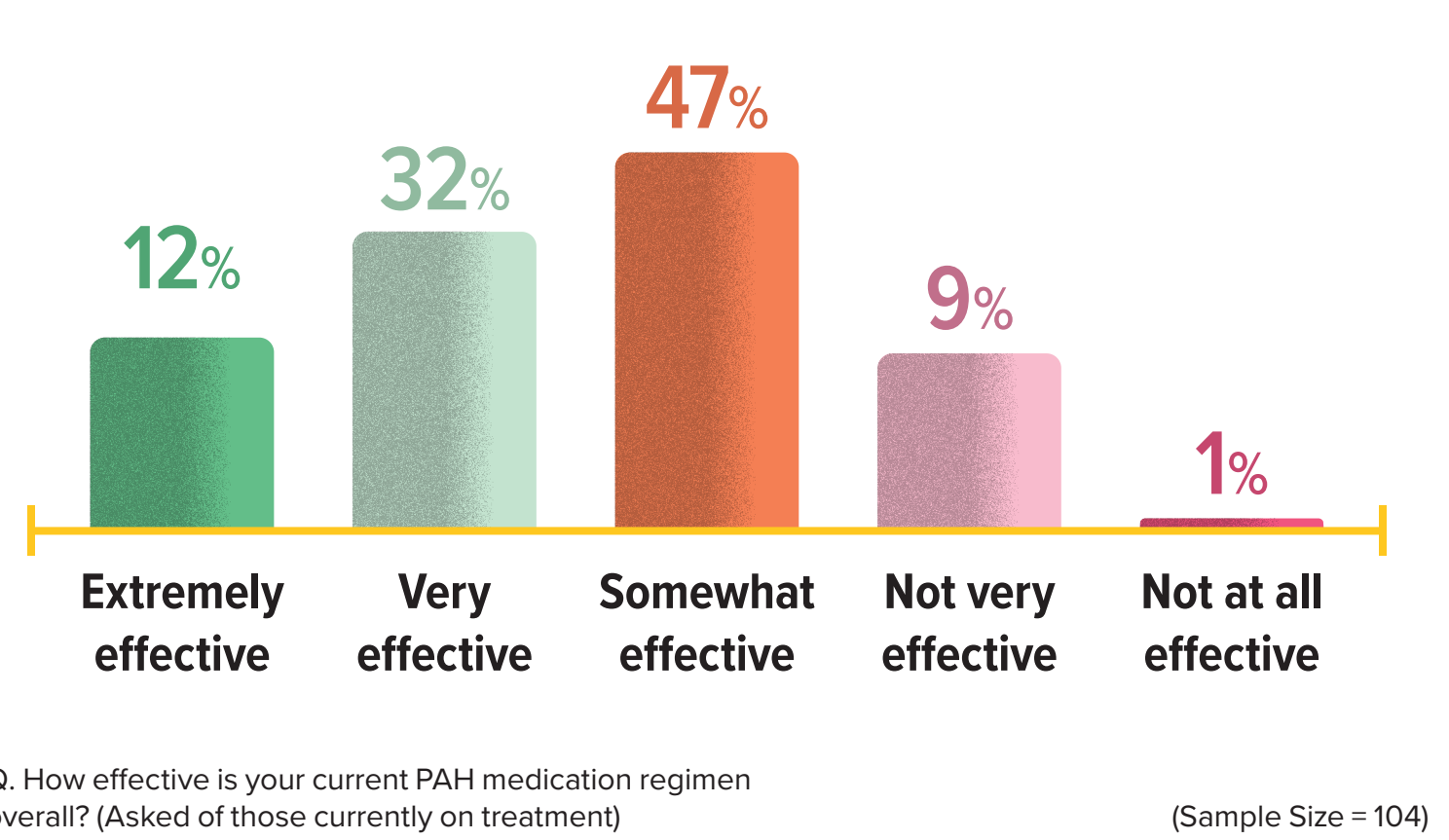


FIGURE 7. Benefits of Treatment Regimen

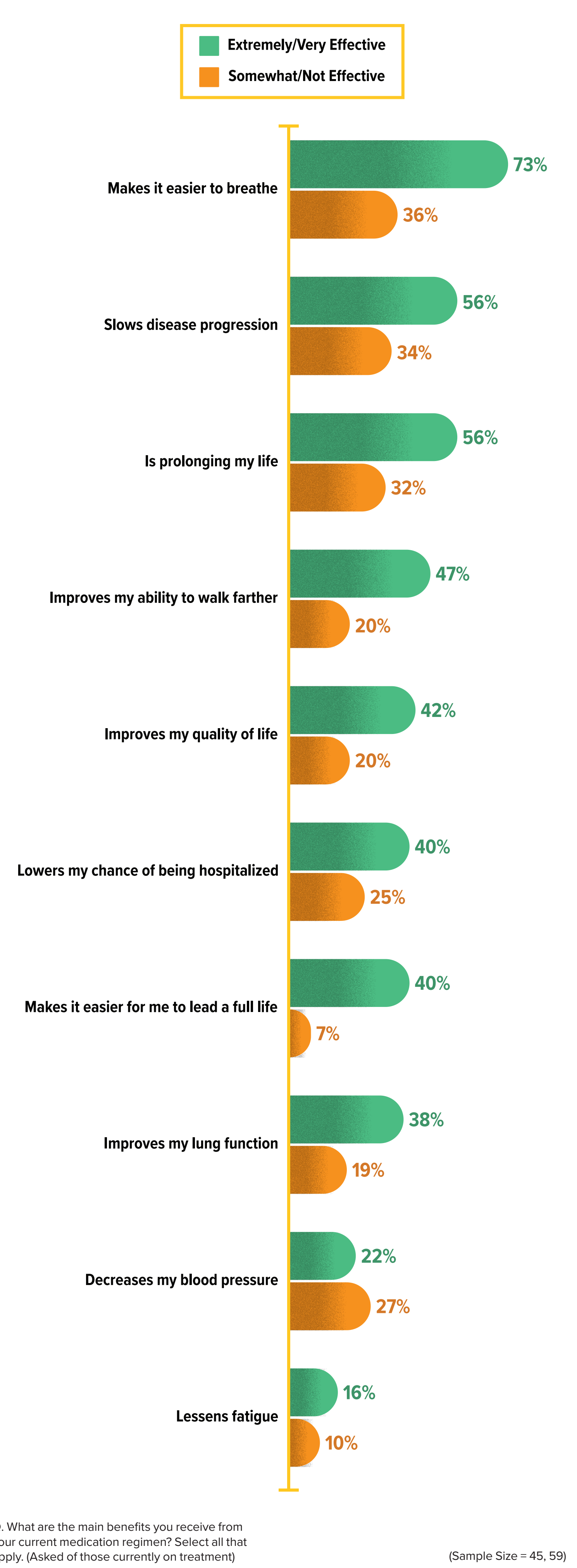


FIGURE 8. Most Appealing Aspect of myPHteam

