



Healthy Bones, Build Them for Life® PATIENT REGISTRY

*Translating Your
Journey to Progress*

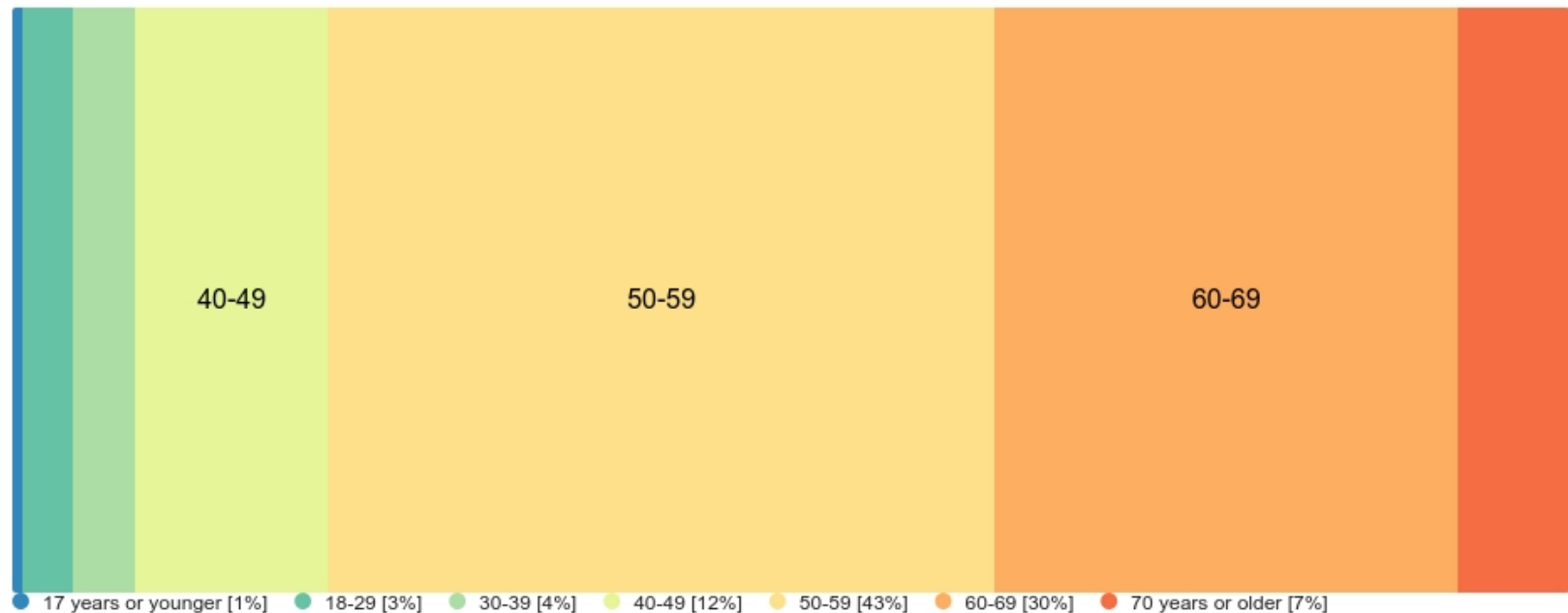
- Goal is to better understand patient preferences, quality of life, and areas of unmet need
- Individuals participate through online surveys
- Overall results are communicated back with participants so that they can benchmark their disease progress
- NOF will shape and share resources based on registry data
- To date, we have distributed two surveys – an intake survey to collect general demographic, disease, and care information and a lifestyle-focused survey

Survey #1: Intake Survey

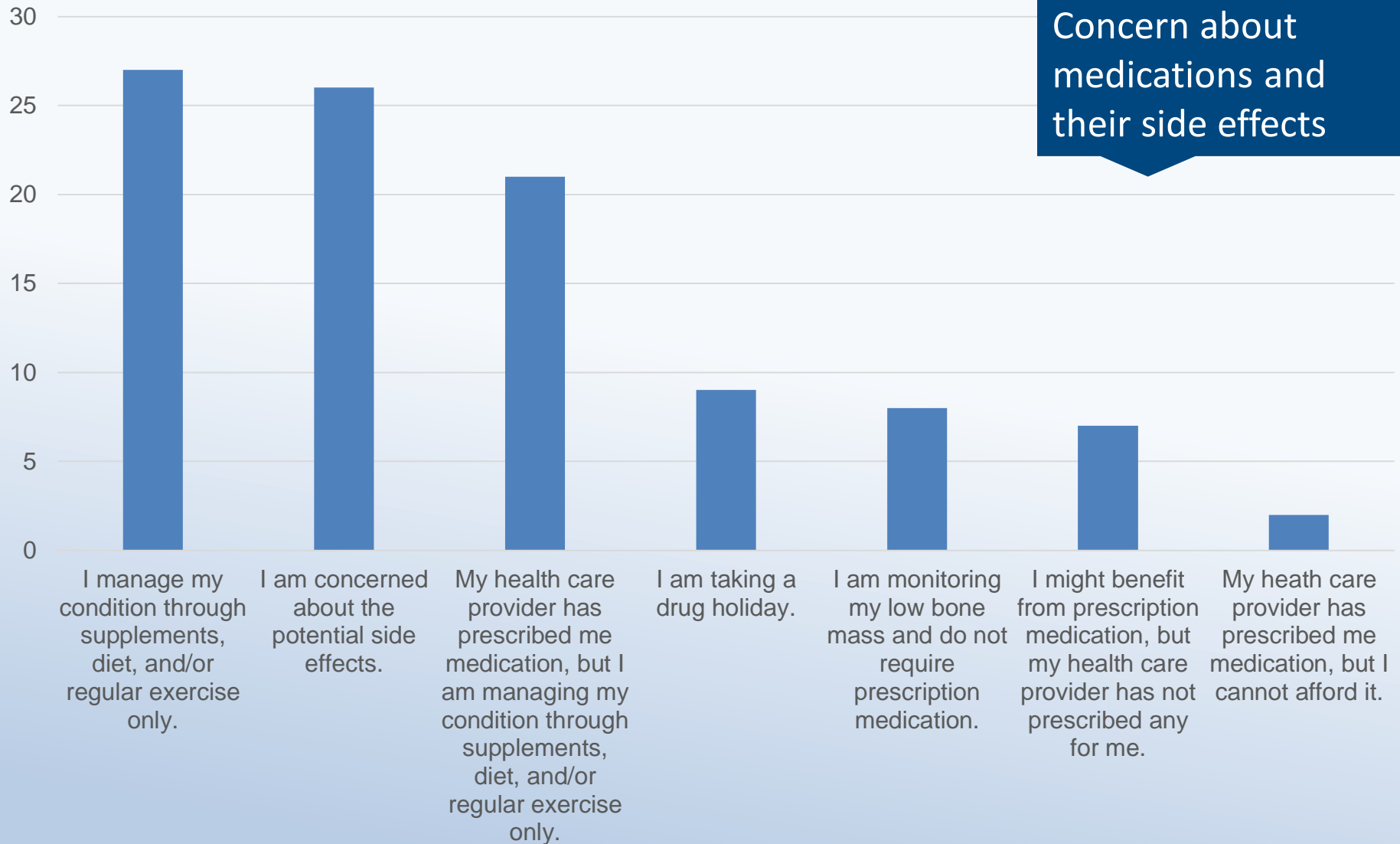
Demographics

- >530 respondents, overwhelmingly female (95%) and white (92%)
- 96% have osteoporosis diagnosis; 4% have osteopenia diagnosis
- Participants are highly engaged in their health care, with 90% of them having had a DXA test in the past 12 months

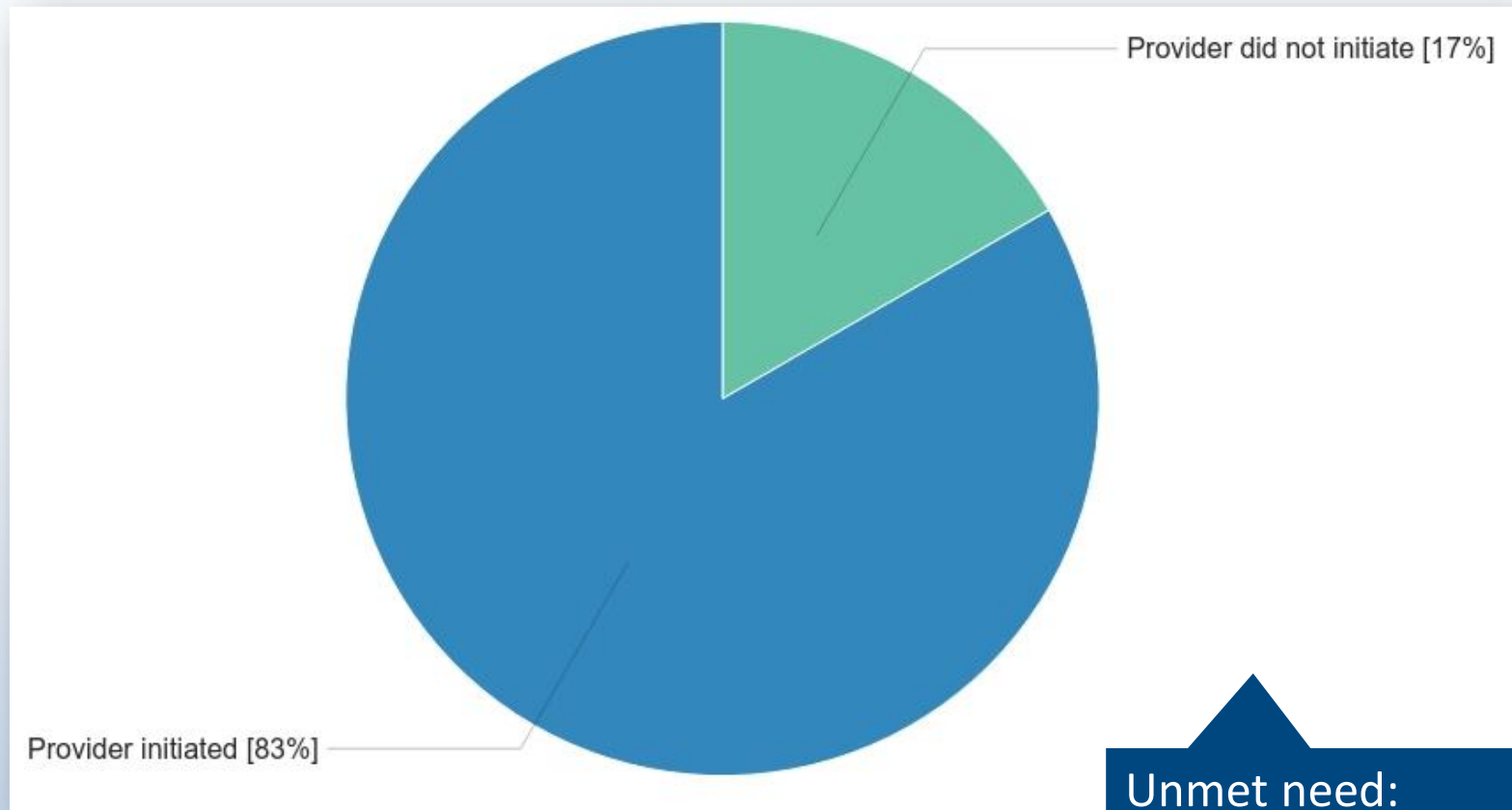
Age of diagnosis



Of the 49% of respondents not taking medications to manage their osteoporosis, their reasons were:



Of the respondents currently on a “drug holiday”



**Unmet need:
Education around
drug holidays**

Survey #2: Lifestyle Survey

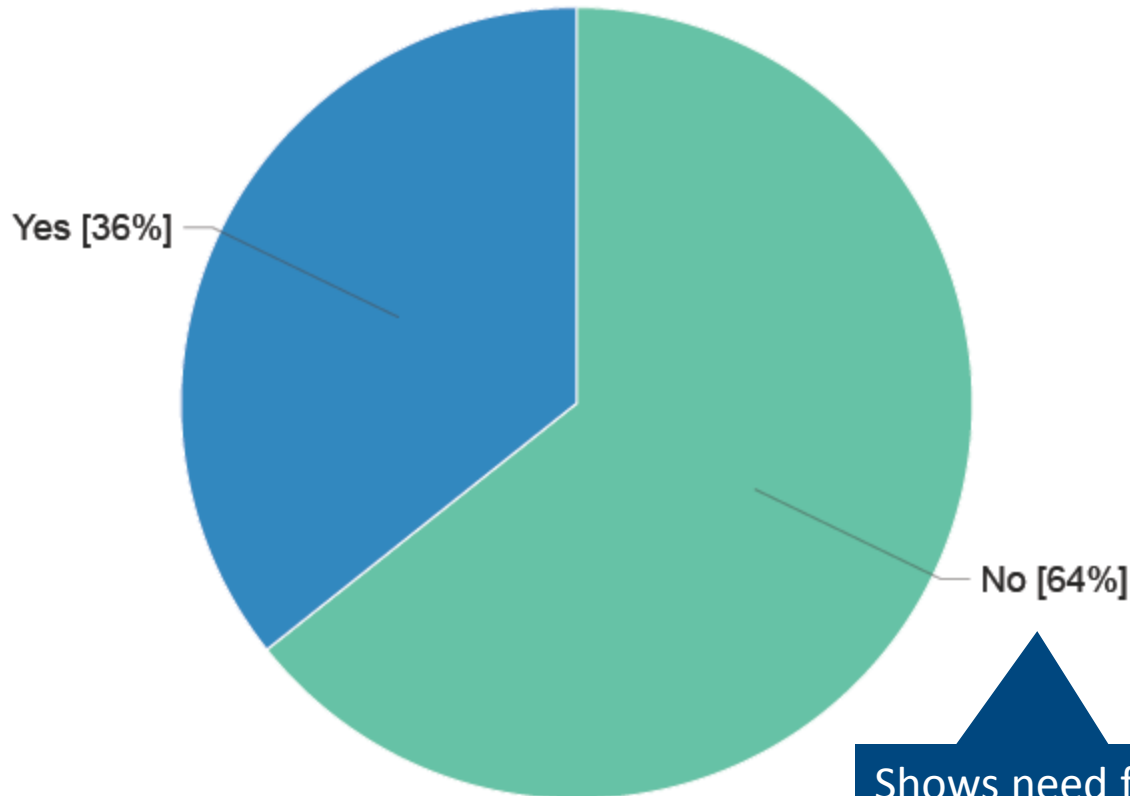
- Lifestyle survey focused on diet, exercise, and ability to accomplish daily activities
- Respondents are knowledgeable about osteoporosis diet recommendations, with 87% report getting the daily recommended amount of calcium and Vitamin D
- Respondents are hopeful around exercise improving their overall health and quality of life, but only a small percentage (36%) receive osteoporosis-specific exercise recommendations
- The most bothersome osteoporosis symptom is loss of height, with 13% of participants always finding it bothersome and 14% sometimes finding it bothersome. Next most bothersome are stooped posture and pain due to spinal fracture, respectively.
- Fear of falling and fracturing is a major concern in this community. Only 35% of respondents reported never being afraid of falling and fracturing a bone. 10% of respondents are “Very much” afraid of falling and fracturing.
- Access to help and transportation are major issues, with 21% reporting that they never have someone to help them if they are confined to their homes and 18% reporting that they never have someone available to take them to see a health care provider.

Reasons why participants feel their general health is better now versus 12 months ago

Exercise is a key to improving patient quality of life



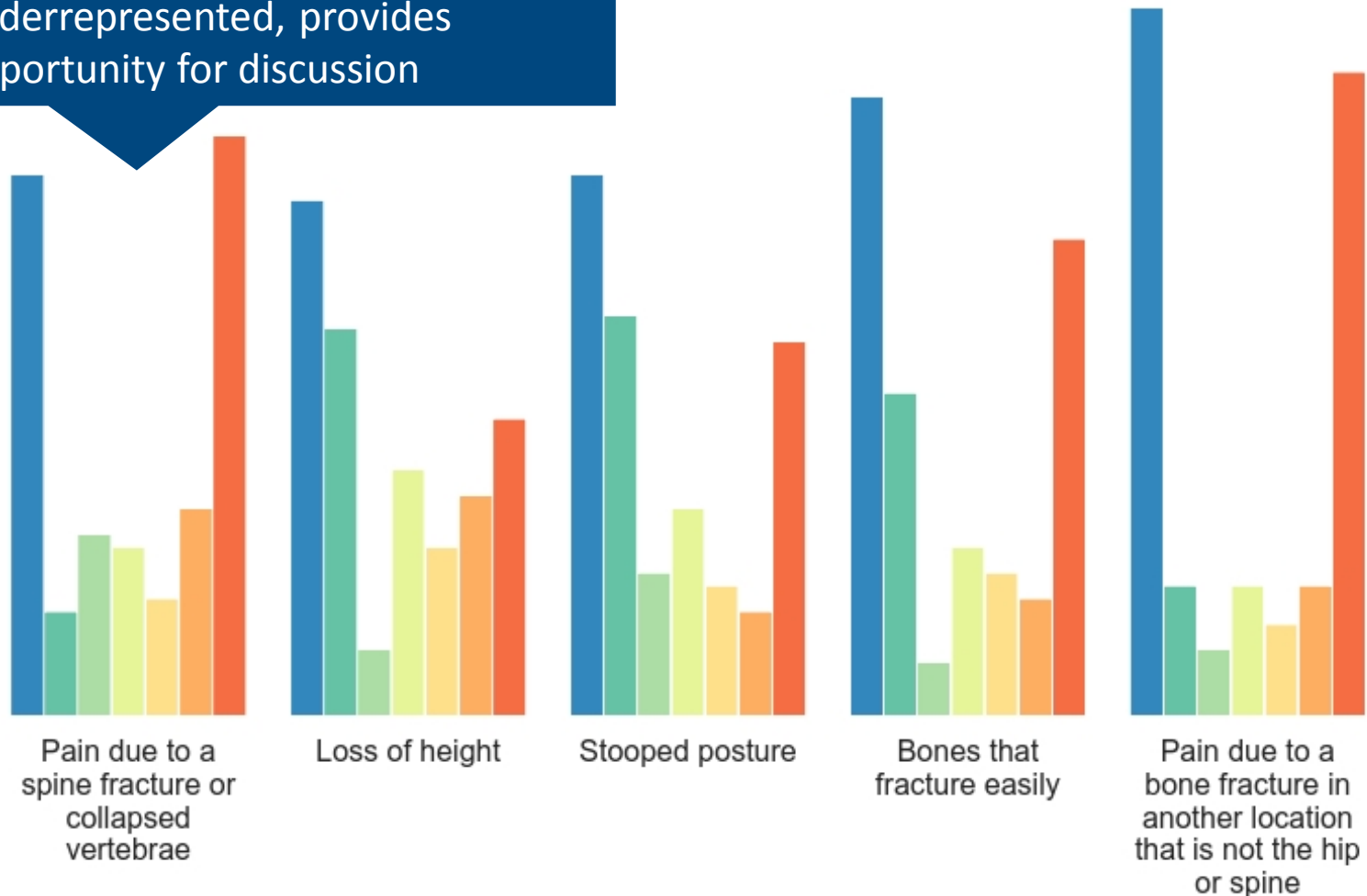
Percentage of participants who report receiving specific recommendations from their health care provider on exercise



Shows need for more wide spread exercise recommendations from health care providers in the bone health field

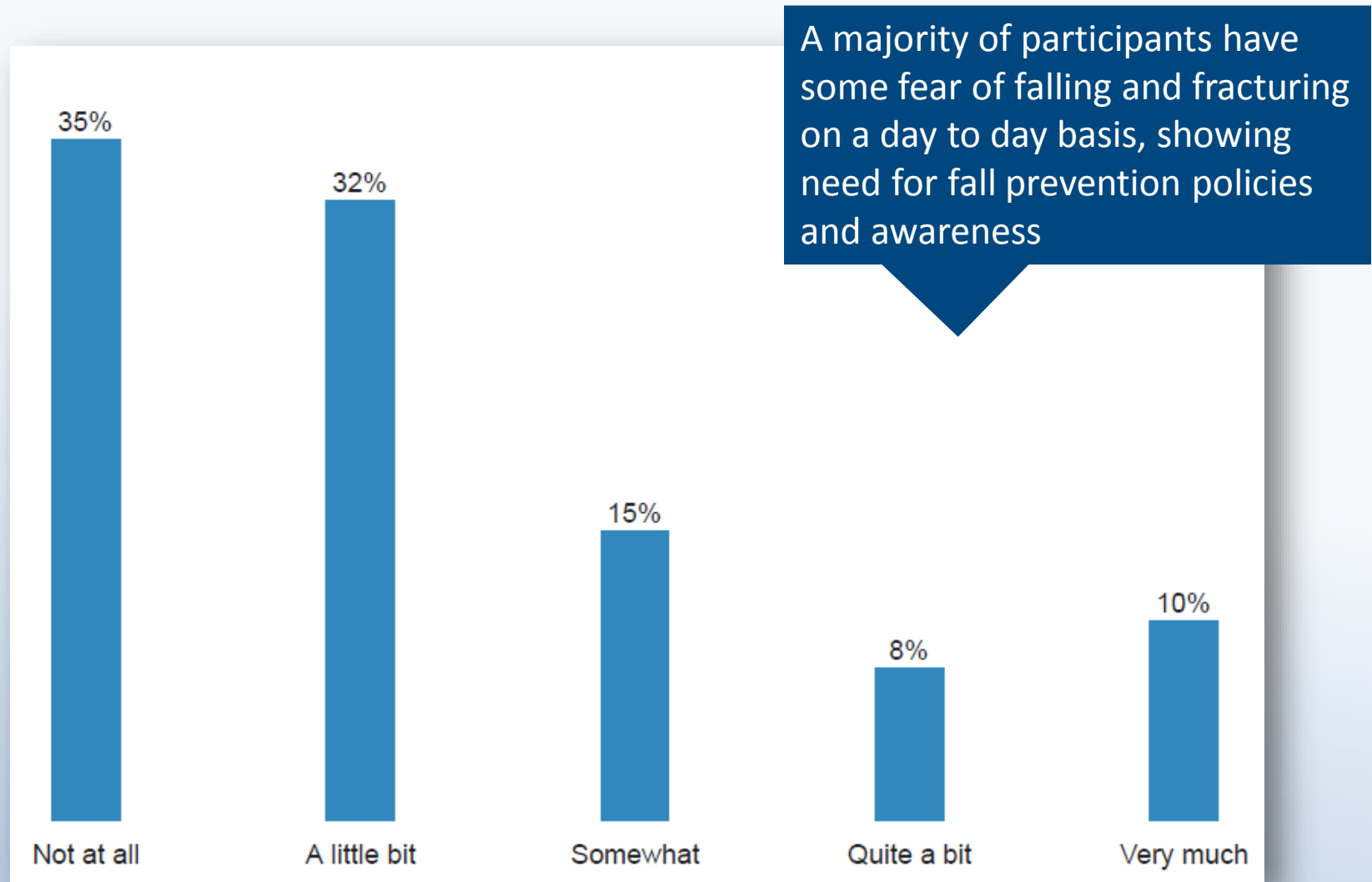
Top bothersome osteoporosis symptoms

Data around osteoporosis symptoms, which are clinically underrepresented, provides opportunity for discussion

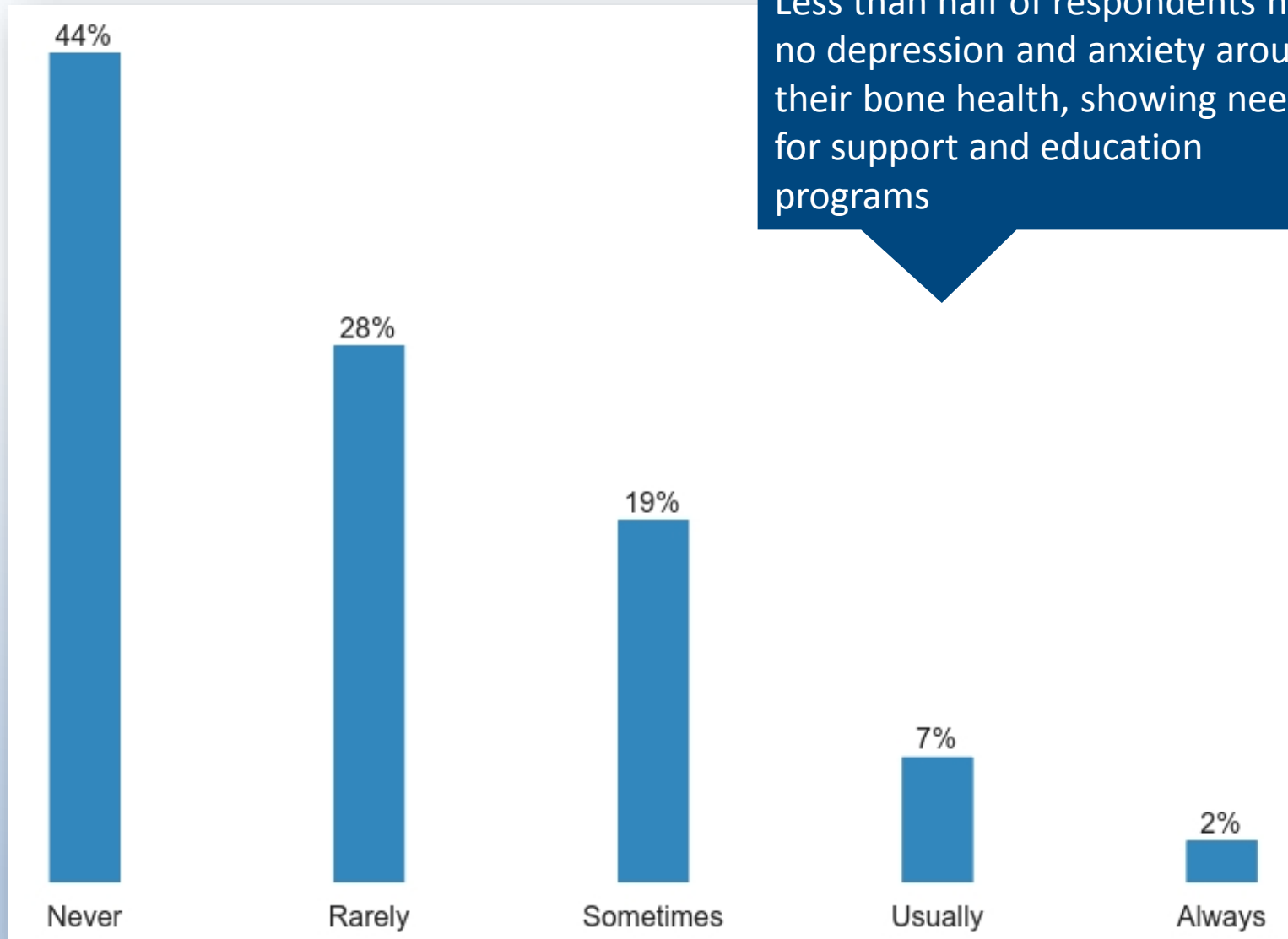


● Not at all bothersome ● Rarely bothersome ● Usually bothersome ● Sometimes bothersome ● Very bothersome
● Always bothersome ● N/A

Degree to which participants say they are afraid of falling/fracturing a bone in their home/office/workplace



How often participants felt depressed/anxious about their bone health issues



Less than half of respondents have no depression and anxiety around their bone health, showing need for support and education programs

The Healthy Bones, Build Them for Life ®
Patient Registry is made possible by those
living with low bone density and
osteoporosis.

Thank you for your participation!