

Patient perspectives on employer-based health insurance: Experiences of employees with chronic diseases

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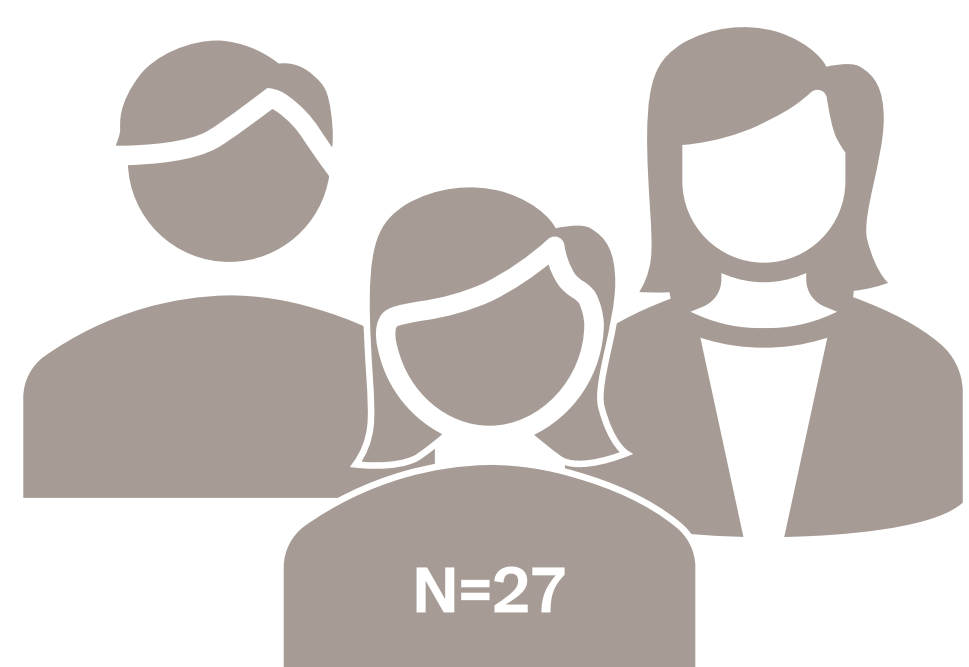
Background

- People with chronic diseases are usually more vulnerable than others to burdens related to healthcare affordability and cost-sharing,^{1,2} and their perspectives should be considered in future decision-making about health insurance (see Poster #11, Neumann et al.)
- However, discussions around health insurance policy, including employer-based coverage, often center around 'average' or healthy individuals and do not consider people with chronic diseases
- Without knowledge of the challenges beneficiaries with chronic diseases face with health insurance (given their unique circumstances and perspectives), employers may be unknowingly overlooking or misunderstanding their employees' experiences

Objective

- To explore the patient experience among adults with chronic diseases who have employer-sponsored health insurance

Methods



Study design

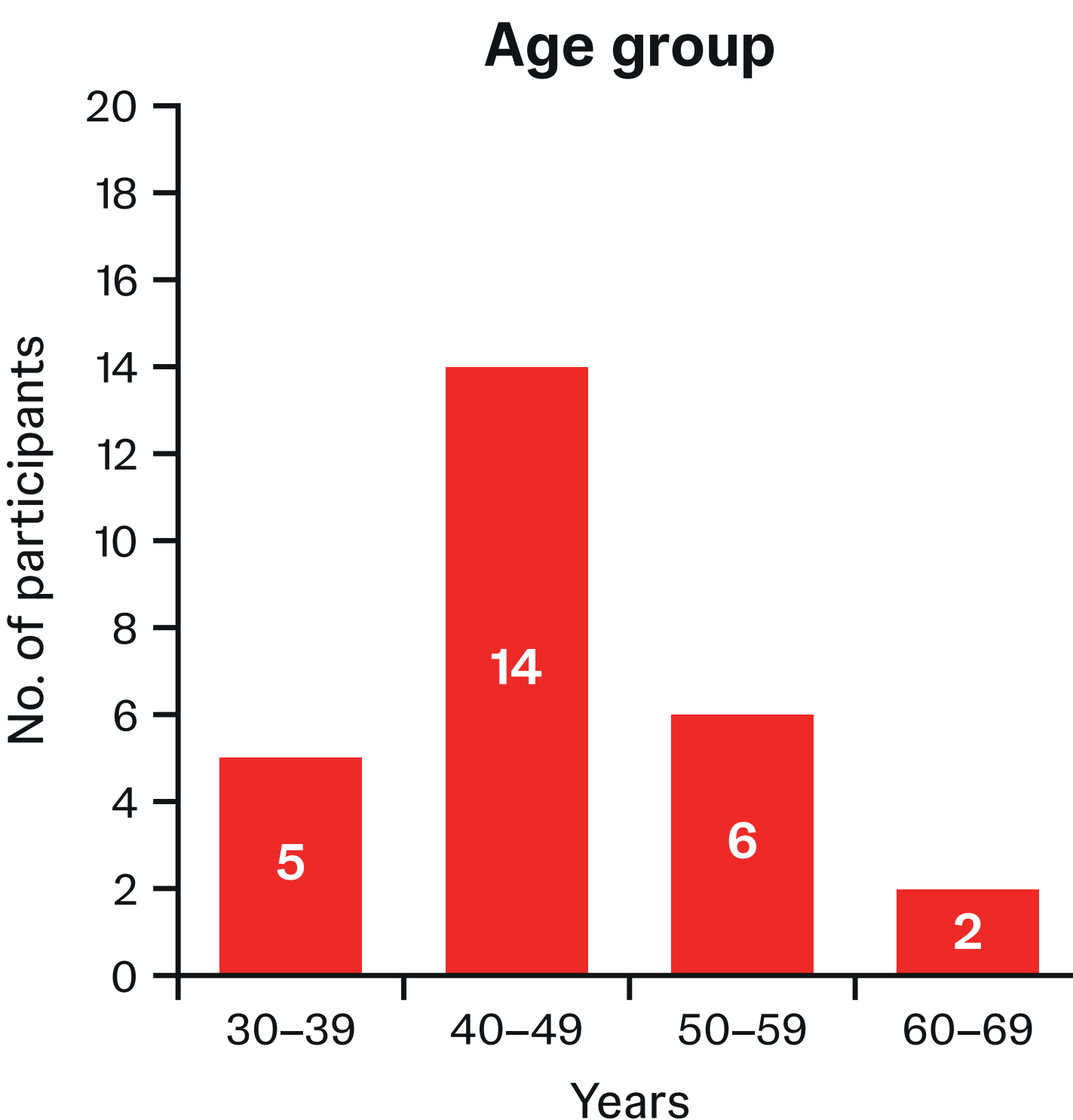
- Participants: US residents living with chronic disease and enrolled in employer-based insurance coverage (as policyholder, spouse, or other family member enrolled in insurance plan)
- Invited from the Johnson & Johnson Patient Engagement Research Councils (PERCs), a program led by Johnson & Johnson that engages a diverse group of patients with chronic health conditions to provide insights through structured research activities³⁻⁵
- Design: 5 in-depth, 120-minute focus group sessions conducted using a semi-structured discussion guide. Key themes were identified from focus group transcripts and direct observations using a narrative analysis framework (MAXQDA software)
- Did not include discussions about specific pharmaceutical products, health plans, or insurance carriers, and researchers were unaware of participants' potential use of particular products or affiliation with specific health plans
- Exempt from institutional review board approval pursuant to the terms of the U.S. Department of Health and Human Service's Policy for Protection of Human Research Subjects at 45 C.F.R. §46.104(d)

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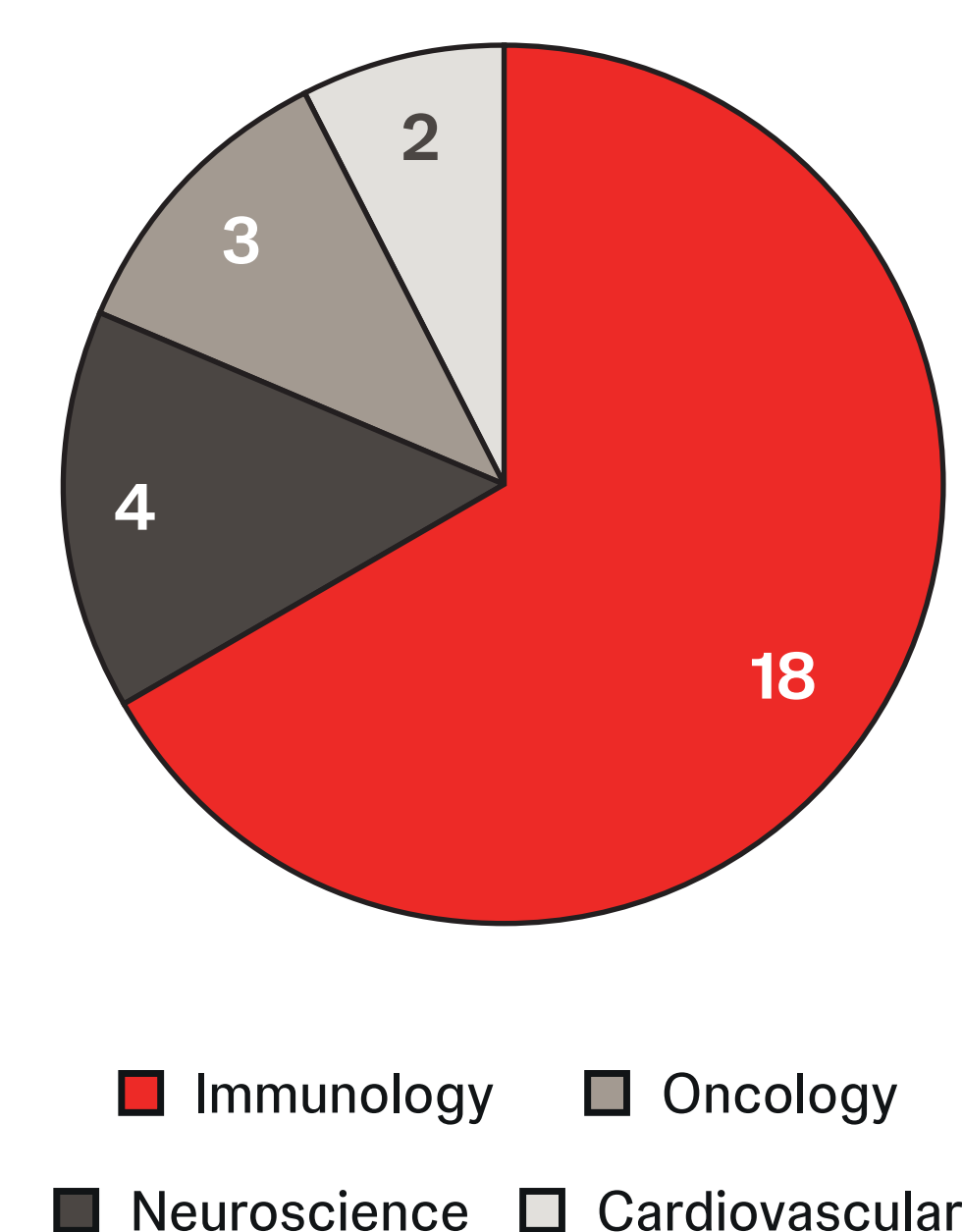
Virtual focus groups

5 sessions 120 minutes

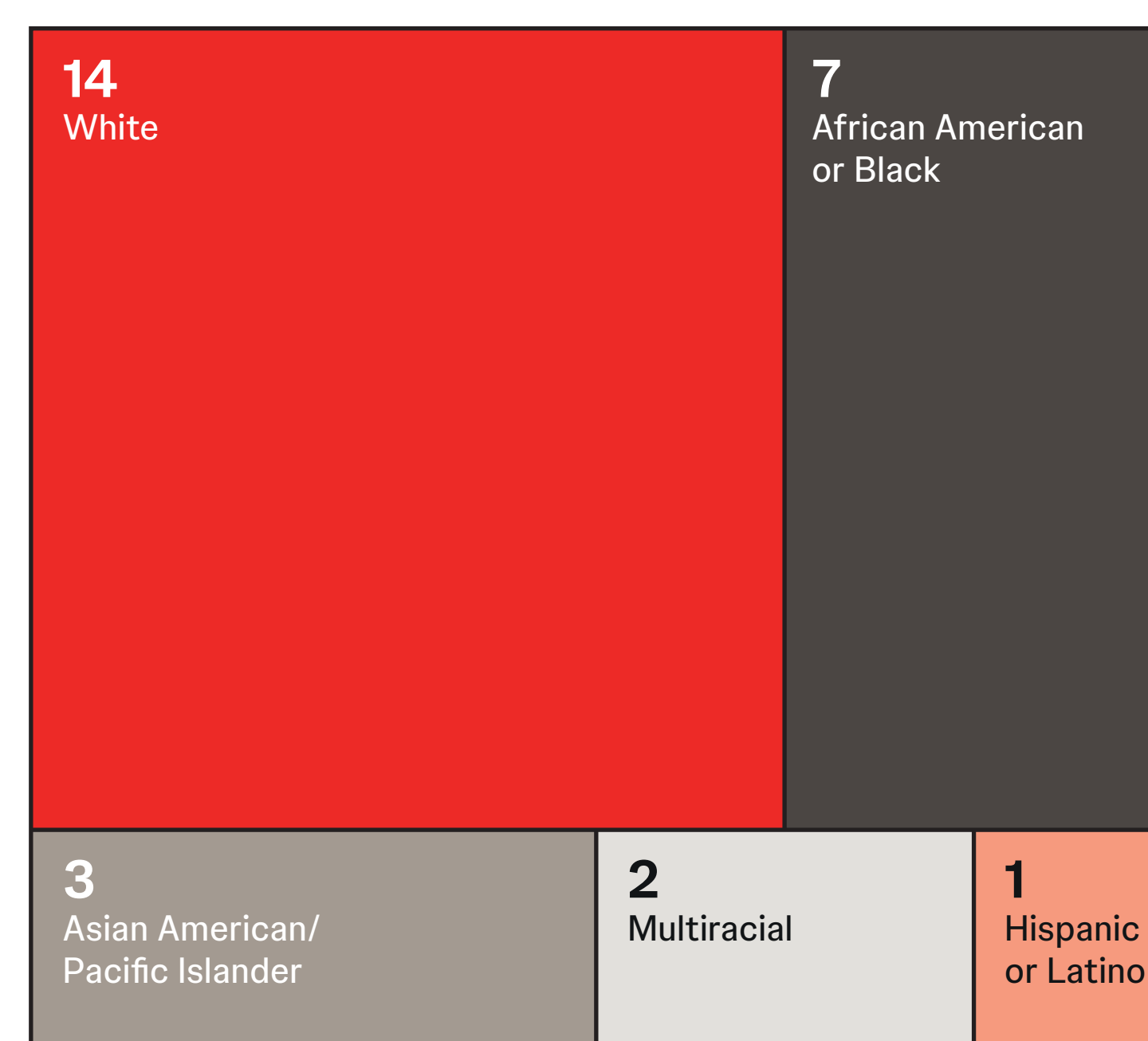
Participant demographics (N=27)



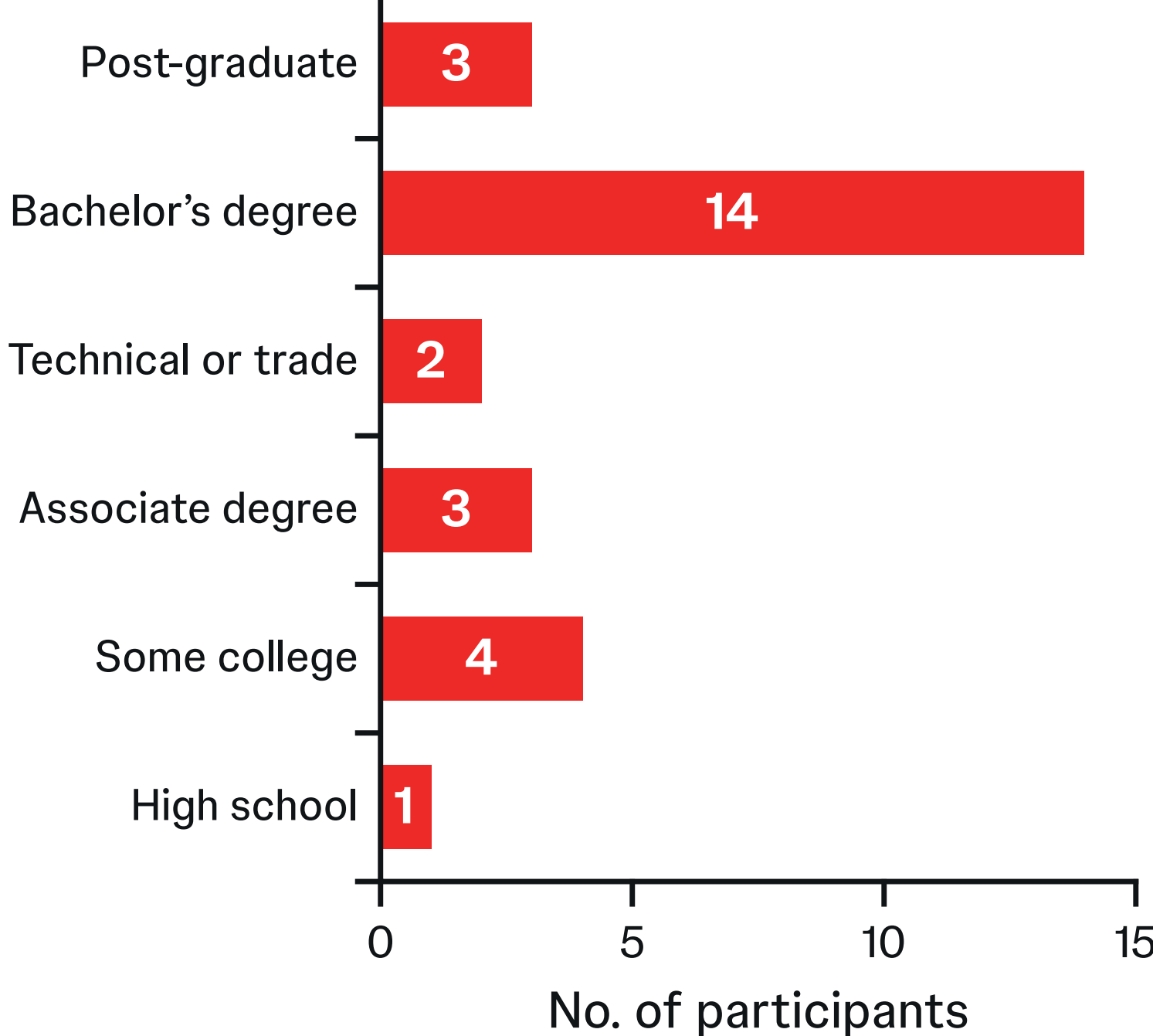
PERC chronic disease category^a



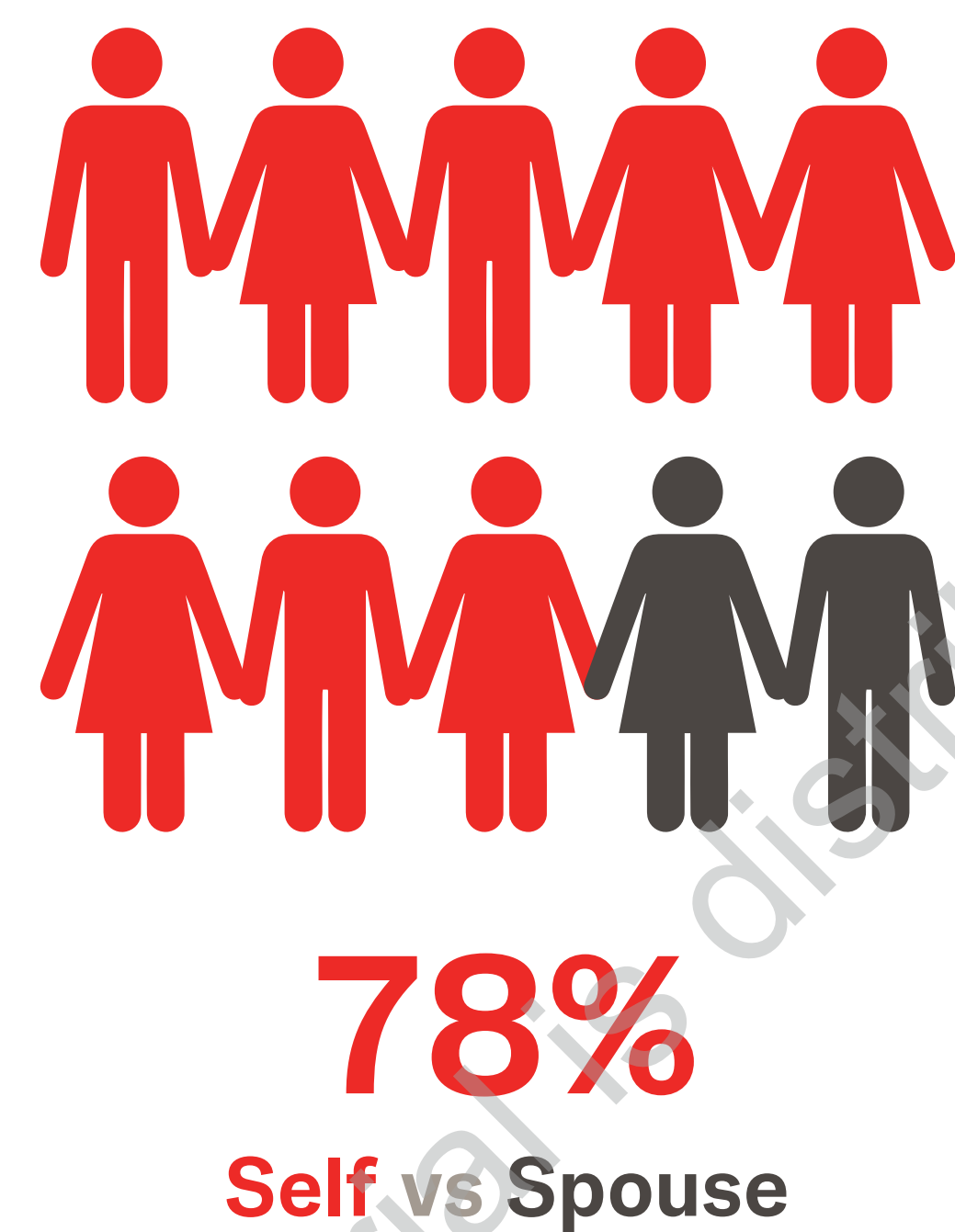
Race/Ethnicity^b



Education level



Policyholder



78%
Self vs Spouse

^aThe cardiovascular category includes peripheral arterial disease and venous thromboembolism; the immunology category includes ankylosing spondylitis, generalized myasthenia gravis, inflammatory bowel disease, psoriasis, psoriatic arthritis, and stem cell therapy; the neuroscience category includes major depressive disorder and multiple sclerosis; the oncology category includes bladder cancer, lung cancer, multiple myeloma, and prostate cancer.
^bPERC members could identify as more than one race/ethnicity. PERC, Patient Engagement Research Council.

Results

Challenges faced by participants

Coverage for chronic needs

- Employer plans often fail to meet complex health needs; most health insurance is perceived to be chosen or designed for healthy individuals
- Limited access to medications and services due to restrictions such as prior authorization can result in stress and participants reported disease worsening
- Beneficiaries with chronic diseases spend a significant amount of mental and physical energy navigating health insurance

“Because of the numbers game, probably 95% of their employees are healthy for the most part, and there's 5% that are really sick that need additional coverage. But ... the vast majority of the employees are OK or don't need all this coverage, then the employer selects the least comprehensive plan at the best savings for them.”

– Participant with generalized myasthenia gravis, age 30–39 years

“My employer suggested the HMO plan, but they always use somebody who's healthy as their model. Somebody who might have one physical a year and maybe a sprained ankle. Not somebody who constantly ... needs bloodwork. I need my blood tested every 3 months. With the high deductible plan, I'd pay thousands of dollars.”

– Participant with inflammatory bowel disease, age 40–49 years

Financial security concerns

- Beneficiaries primarily expect that health insurance will provide high-quality coverage if they pay higher premiums upfront
- However, opinions were divided on whether health insurance offers true financial protection in the event of an unforeseen healthcare event
- Those who are not confident that their insurance plan offers financial protection feel that they are just a single emergency or one hospitalization away from financial hardship and possible bankruptcy
- Health insurance changes made by the employer for the overall population of beneficiaries (such as changing carriers year to year) may seem minor or be viewed as financially sound decisions, but they can have a significant impact on those with chronic diseases

“I pick the most expensive, best plan just because I know that I will use it. I know that I need, that my life has been saved multiple times by just having insurance. I think that I have to do that. I guess just a, it's a finance thing. I know that if I pick a high deductible, I'm going to end up paying that huge deductible.”

– Participant with major depressive disorder, age 30–39 years

“I don't think that my employer understands all of the factors. ... What I would want employers to understand is every time they're just like, 'Oh, we're going to shop around and find a cheaper plan,' it's such a stressful disruption that could pull the rug out from under my health and finances.”

– Participant with inflammatory bowel disease, age 30–39 years

Enrollment and communication gaps

- Short enrollment windows hinder understanding of plans and their impact on health needs
- Resources offered by the employer during open enrollment are geared towards beneficiaries without chronic diseases
- Those who are offered a single plan feel limited in their options
- Little information is provided to the beneficiary after enrollment
- Most participants feel uncomfortable discussing concerns with their employer due to fear of discrimination
- Those who are comfortable expressing their concerns perceive their employer to be uninformed about health insurance design and unable to help
- Most employers do not ask about the employee's experience with their insurance plan

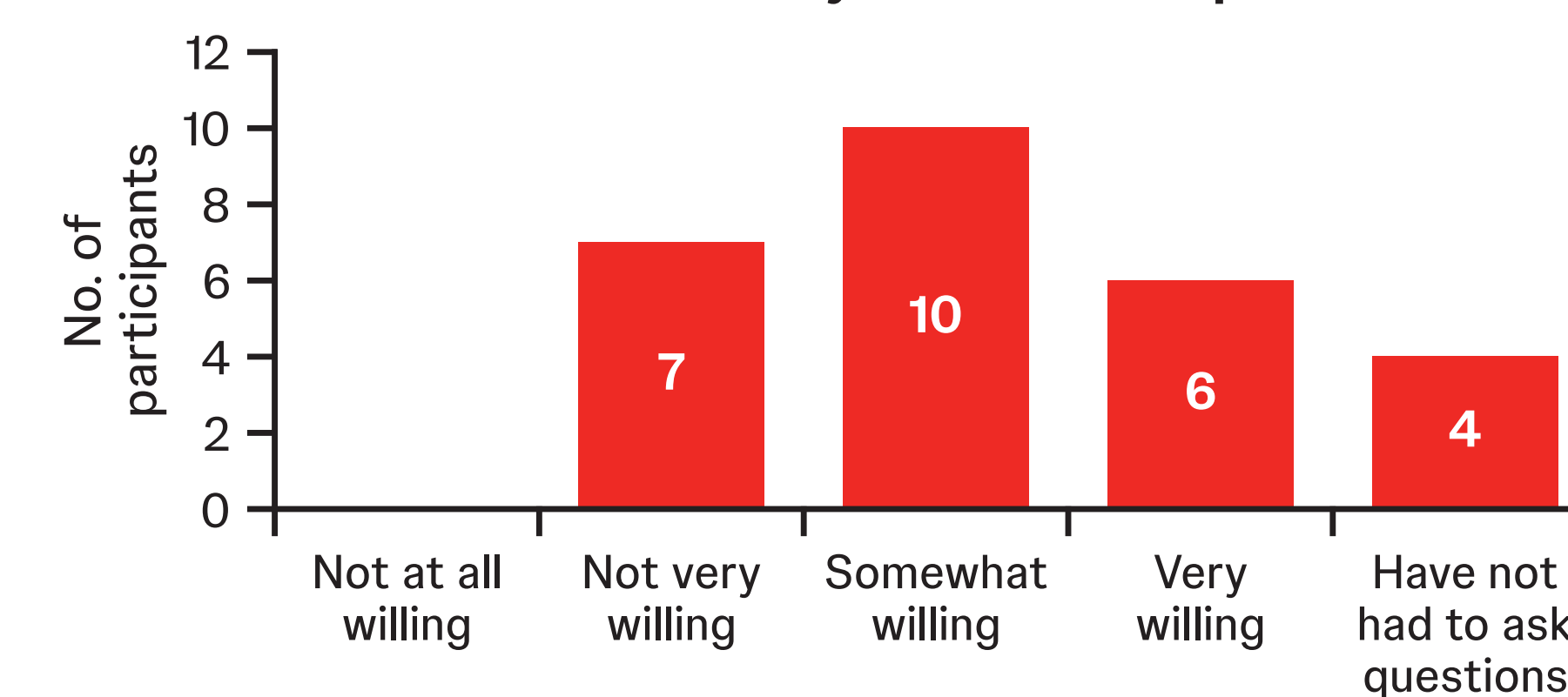
“I feel like employers could do a lot more to be transparent, but are the employers really the ones to help me as a patient? I don't think so. I think it's bigger than that; it's the insurance companies because I can go to my HR person all day, and she only has the information that she's sharing from what's available to her. It's really not going to change.”

– Participant with inflammatory bowel disease, age 40–49 years

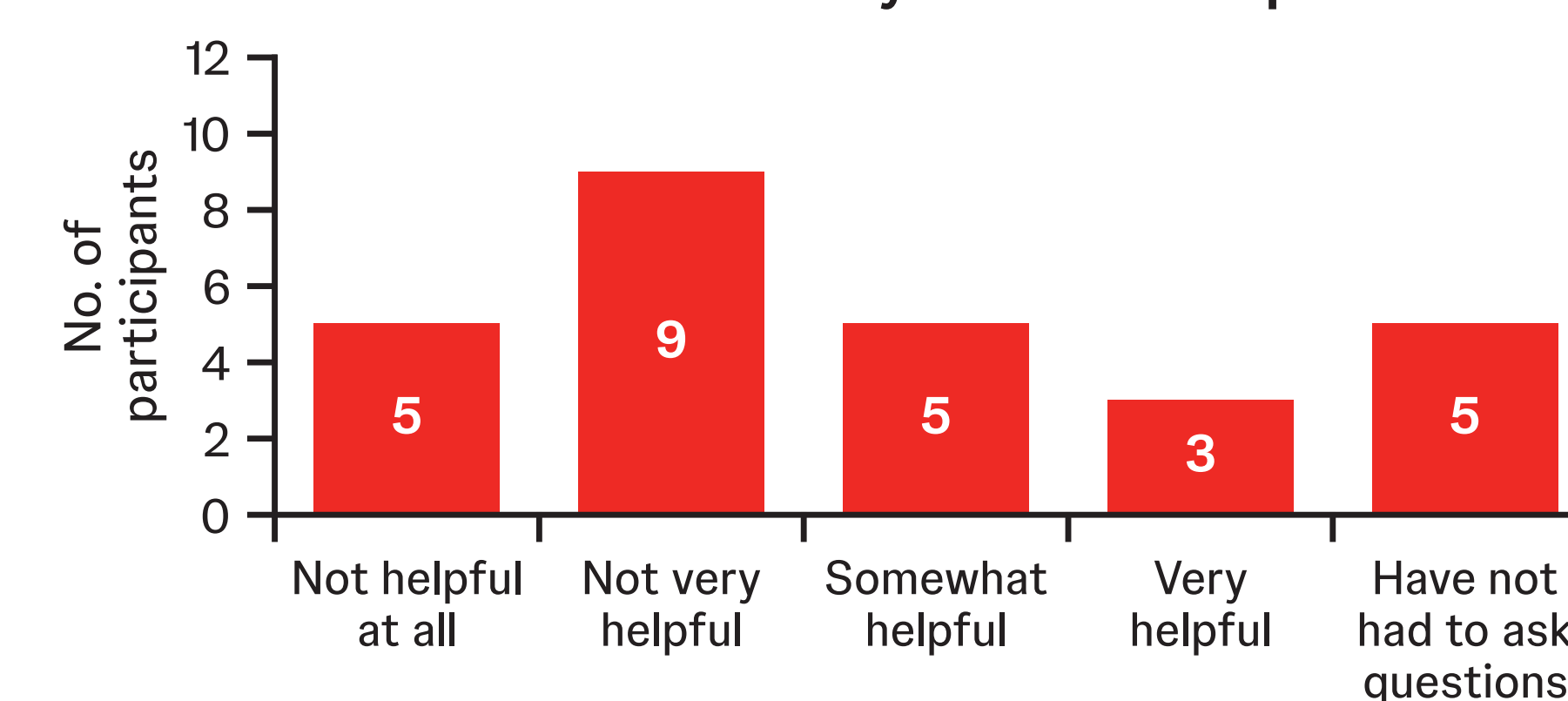
“I think we should have at least two other plan choices available. ... Not everybody is a 'one size fits all.' There are people that simply need the insurance just to have it. ... They're healthy. ... And then there are others that may have health issues, high blood pressure, and diabetes that may require more visits to the doctor.”

– Participant with multiple myeloma, age 50–59 years

How willing is your employer to address questions and concerns related to your insurance plan?



How helpful is your employer when addressing questions and concerns related to your insurance plan?



The employee–employer health insurance relationship

- The employee–employer relationship regarding health insurance ranged from being a positive experience to feeling virtually non-existent for some
- Chronic illness shapes job satisfaction and perceptions of employer support
- Many feel 'stuck' in current jobs due to health insurance concerns

“Insurance is just as important as pay if I go looking for a new job. ... And I would advise all of us to look into these things.”

– Participant with multiple myeloma, age 50–59 years

“And the problem is when you're interviewing for another job, they don't go into that much detail about the medical benefits. It's like a red flag if I start asking too much about that. So that's why I'm still employed where I am because I'm trying to learn how to ask those questions in interviews without revealing that I have medical issues.”

– Participant with peripheral arterial disease, age 40–49 years

Participant recommendations for improvement

- Enhance employer training on chronic disease complexities
- Offer tailored health insurance options for diverse health needs
- Increase transparency about costs and plan changes
- Create opportunities for employees to have open discussions with their employers or with neutral third parties who know about chronic diseases and health insurance

Gather and act on beneficiary feedback to improve plan design

“It would be beneficial for employers or companies, before the enrollment period, maybe spring or summer, to have a lot of sessions where you can make an appointment with a representative from the company and talk about your specific situation and ask those questions so that you can get the best coverage for your situation.”

– Participant with inflammatory bowel disease, age 40–49 years

Conclusions

- Participants report that employer-based health insurance often fails to meet the needs of beneficiaries with chronic diseases
- Plans are often perceived as catering to healthy beneficiaries, not to those with chronic diseases
- Beneficiaries with chronic diseases seek transparency, better communication, and understanding and acknowledgment of their needs

Key takeaway

- Employers should try to prioritize tailored insurance options, transparent communication, and open dialogue to better support employees with chronic conditions

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Disclosures

BD, UN, YF, and RG are employees of Johnson & Johnson and hold shares in the company. WP is an employee of Evidera, which helped to conduct the research with funding from Johnson & Johnson.



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