

The patient voice in policy research: leveraging qualitative data to understand how policy impacts patients

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Introduction

- Patients are key stakeholders in healthcare; as such, their involvement in shaping healthcare policy is important to provide a contextual perspective around its viability, practicality, and appropriateness
- Qualitative research can capture rich data on patient perspectives, experiences, and behaviors¹.
- Qualitative research is particularly well suited to understand patient interactions with policies to inform policymaking; yet there is a paucity of research in this space²
- In recent years, there has been increased emphasis on including patients as integral members of the research team, from drug development and regulatory

decision-making,³ to shared decision-making at the patient–provider level,^{4,5} as well as publication planning and development⁶

- There is a need to include patient perspectives at a higher organizational/policy level to inform broader policies that may impact access to treatment

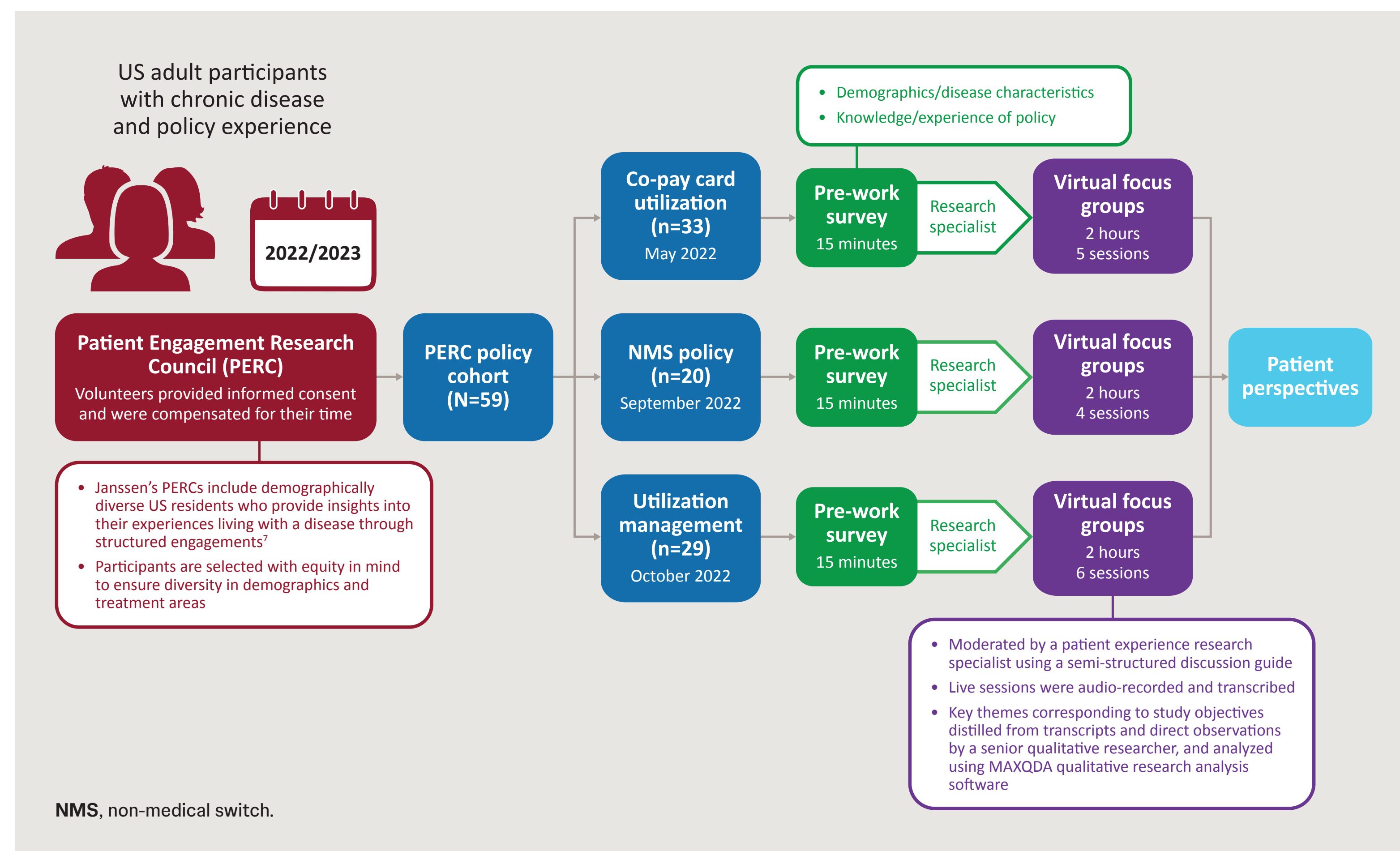
Objectives

- To evaluate how US healthcare policy impacts patients with chronic disease through exploratory focus groups, and to pilot internal guidance on compliant processes for the publication of patient perspectives as well as the inclusion of patients as authors

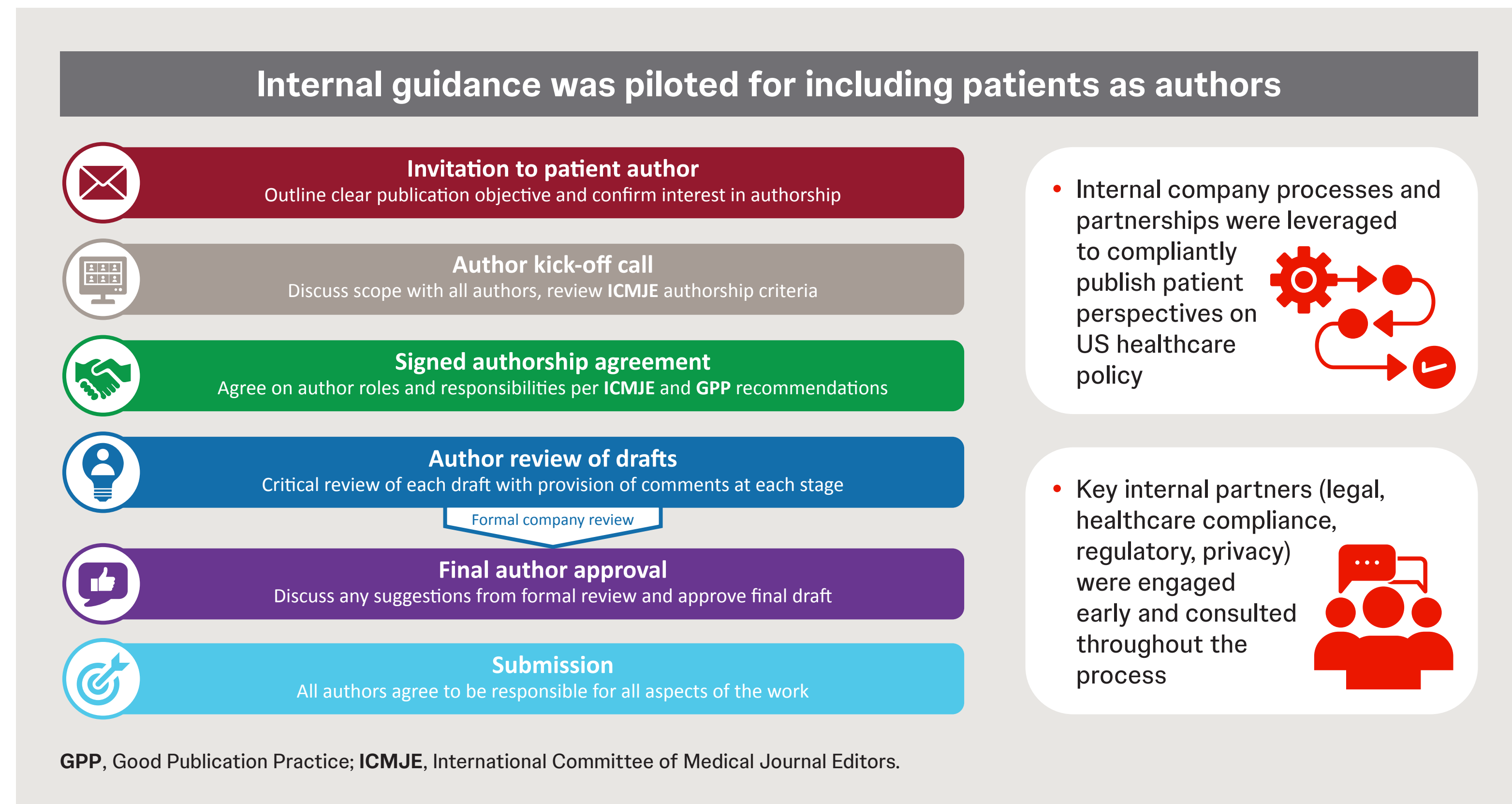
Methods

Qualitative exploratory focus groups

- Patients with chronic conditions invited through Janssen's Patient Engagement Research Council (PERC) program⁷ discussed the impact of US healthcare policy through participation in three engagements
- The following inclusion criteria were considered for each of the three engagements:
 - Co-pay card utilization:** PERC members with experience using a pharmaceutical manufacturer co-pay card or coupons in the past 12 months
 - Non-medical switch (NMS) policy:** PERC members were divided into two groups based on whether they had or did not have NMS experience
 - Utilization management:** PERC members with at least one experience with prior authorization, step edits, or formulary exclusion lists

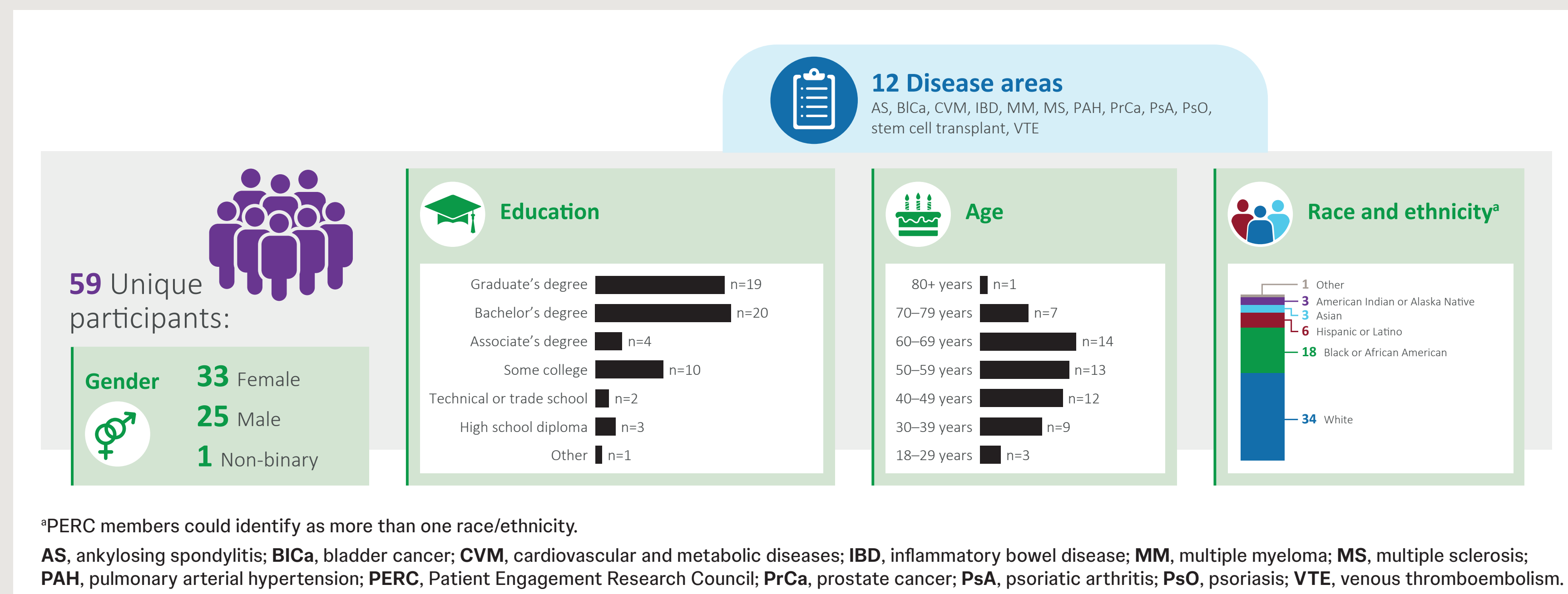


Compliant publication of patient perspectives

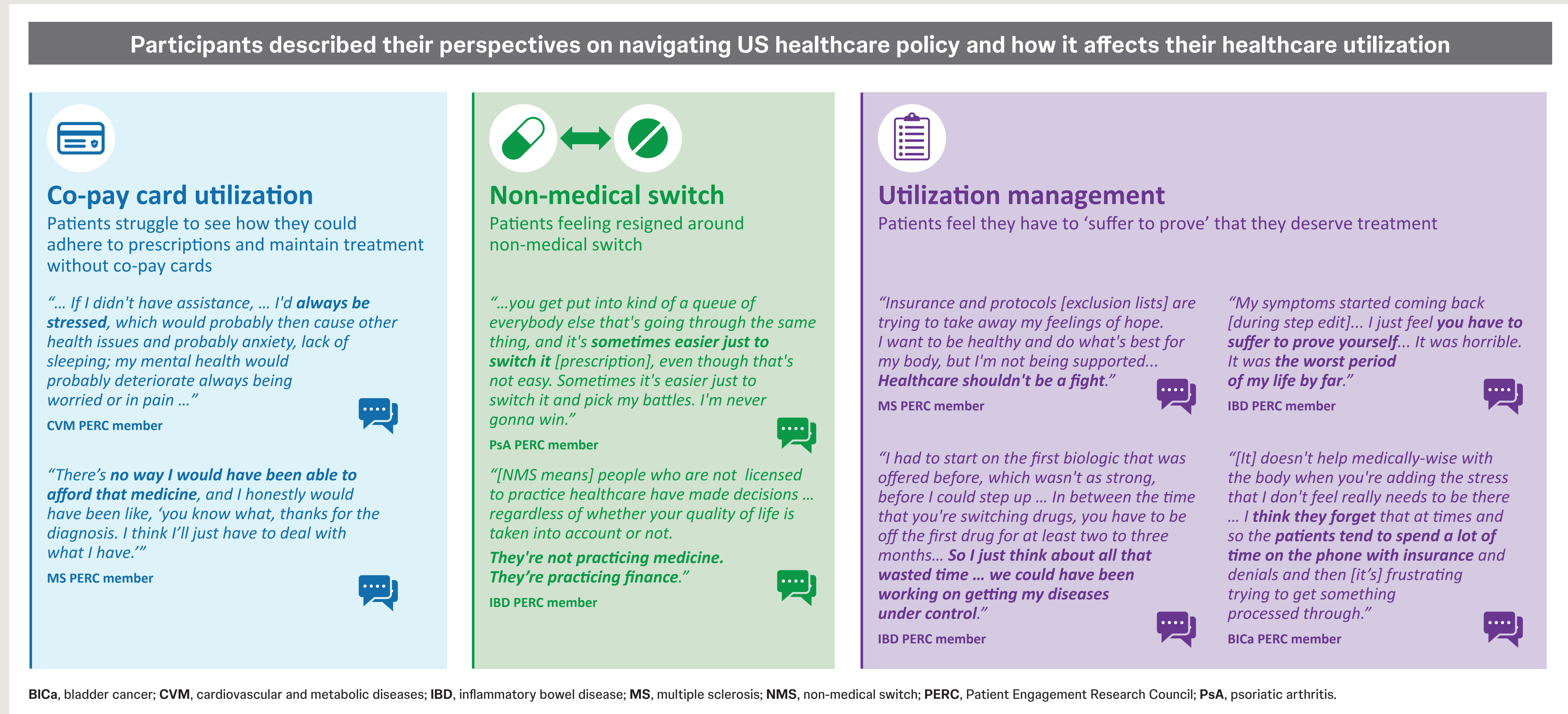


Results

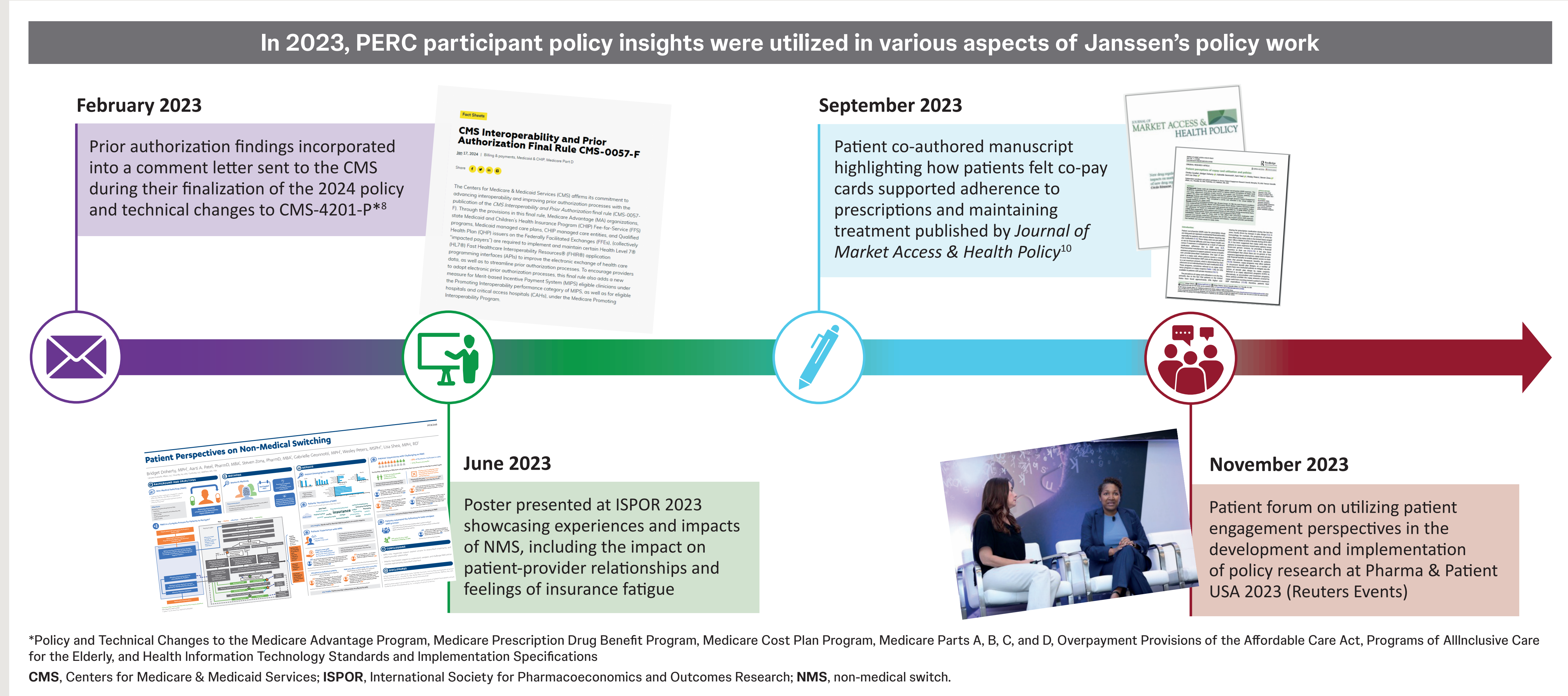
Participant demographics and clinical characteristics



Patient perspectives on US healthcare policy



Sharing patient insights on US healthcare policy



Conclusions

- ✓ Patient experience can enhance understanding around how policy impacts patient access to (or experience with) healthcare
- ✓ As patients are experts in their disease area, their experience and perspectives should be included in scientific publications to provide the lived experience around policy decisions
- ✓ These results highlight how developing internal capabilities and processes are critical to better incorporate the patient voice into policy making and evaluation

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Disclosures

DC is an independent consultant and a contract consultant with Janssen Scientific Affairs, LLC, a Johnson & Johnson company, and has been diagnosed with multiple sclerosis. LS and BD are employees of Janssen Scientific Affairs, LLC, a Johnson & Johnson company. WP is an employee of Thermo Fisher Scientific, Inc. (formerly CorEvitas, LLC), which derives its profits from interactions with pharmaceutical sponsors.



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