Challenges in PNH and CAD Management Revealed through Educational Interventions over Three Years

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AA·MDS INTERNATIONAL FOUNDATION

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INTRODUCTION

Paroxysmal nocturnal hemoglobinuria (PNH) and cold agglutinin disease (CAD) are rare, hemolytic anemias that present challenges in clinical practice, particularly related to diagnosis and an evolving therapeutic armamentarium. To improve clinical decision-making and understand practice barriers among clinicians who care for patients with these non-malignant hematologic disorders, educational initiatives in PNH and CAD were designed in collaboration with the National Organization for Rare Disorders (NORD).
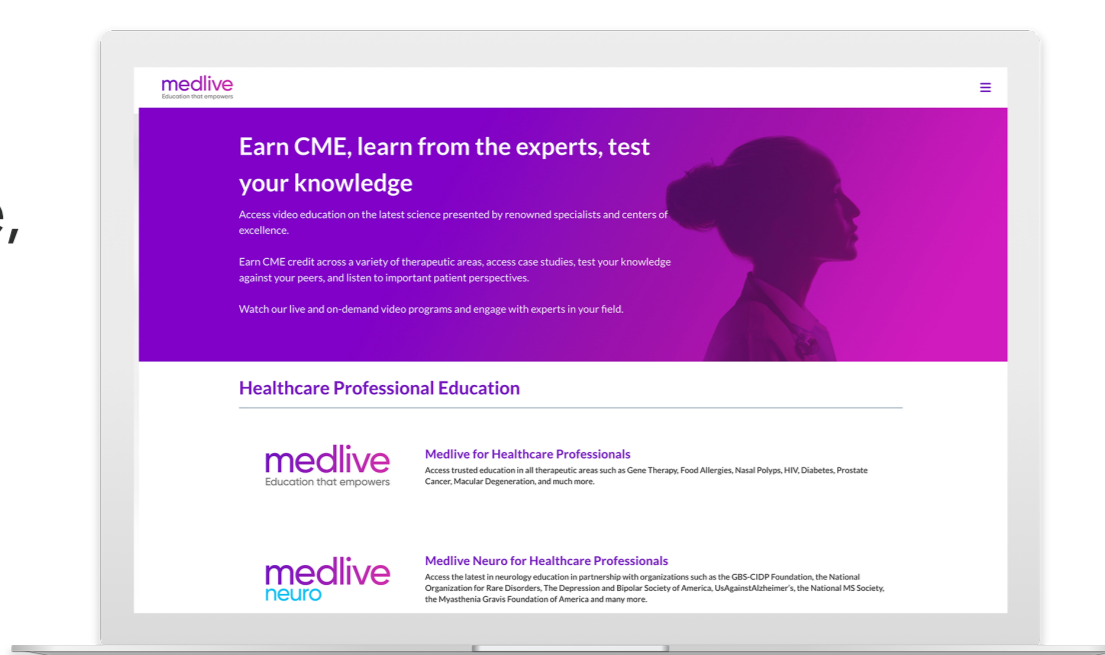
METHODOLOGY

Interventions

Four online certified medical education (CME) activities released between 2020 and 2023: Each focused on PNH and CAD. PNH activities were a 30-minute endured CME activity launched April 2022, and a 90-minute live broadcast and subsequent endured CME activity launched May 2022. The CAD activities included a 60-minute live and endured CME activity launched October 2020, and a 30-minute endured CME activity launched April 2022. All activities were available on-demand for 12 months. Expert hematologists led each faculty panel. To expand the reach of PNH education, micro-learning videos (2-4 minutes), each tied to a learning objective, were posted to LinkedIn targeting NPI-verified oncologists.

Partners

Advocacy groups: National Organization for Rare Disorders (NORD), Aplastic Anemia and MDS International Foundation (AAMDS)
Education: PlatformQ Health and Global Education Group
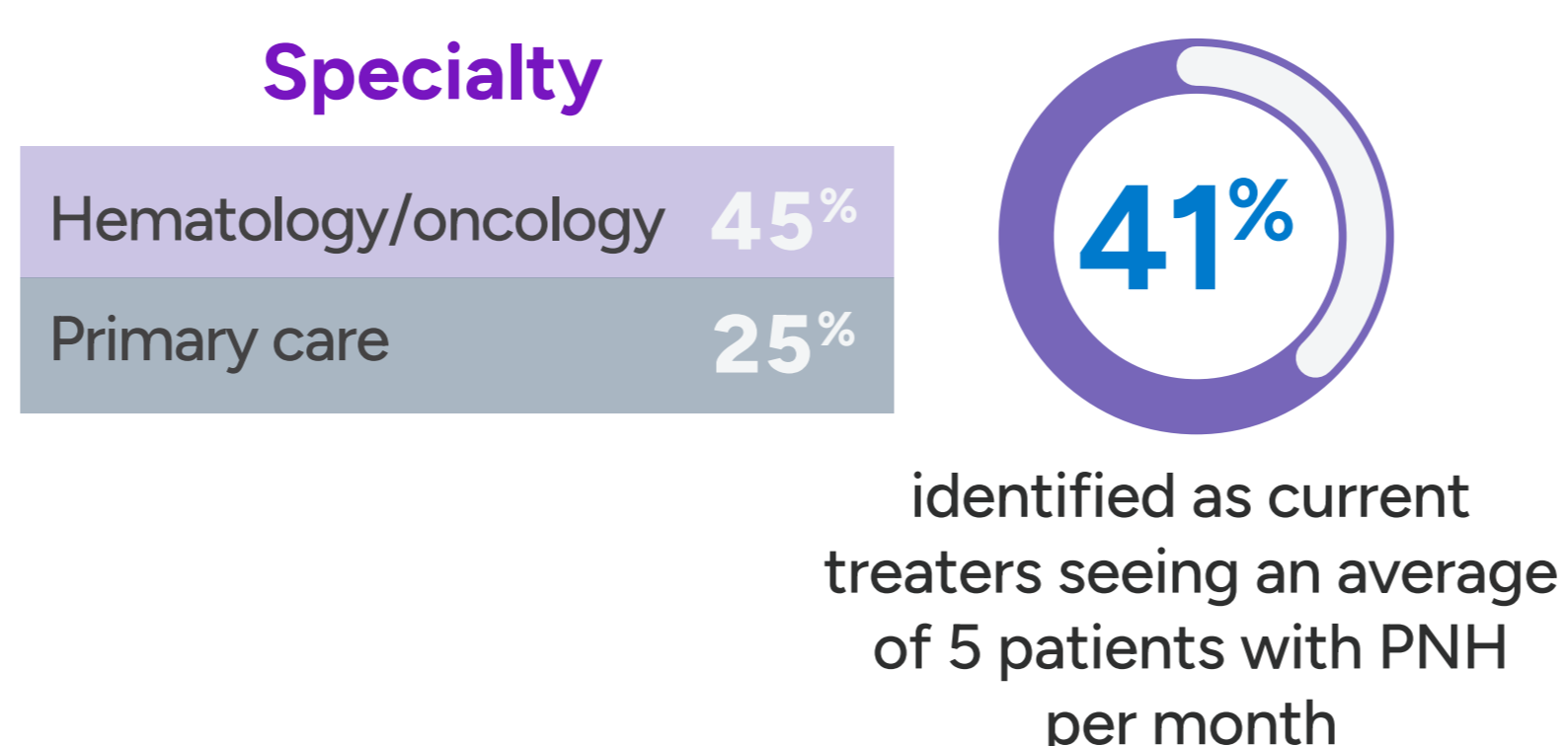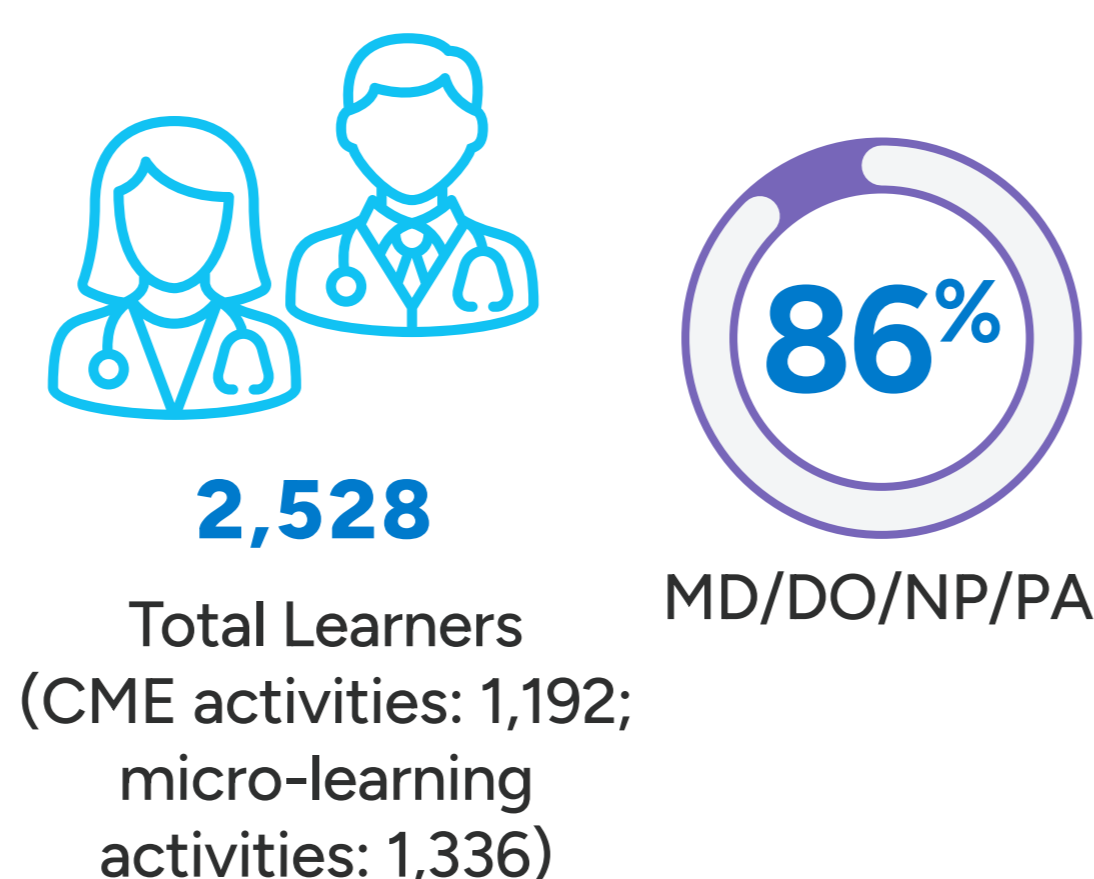
Data Collected

Changes in knowledge, competence, reported behavior, engagement, identification of continuing gaps, and learning retention.
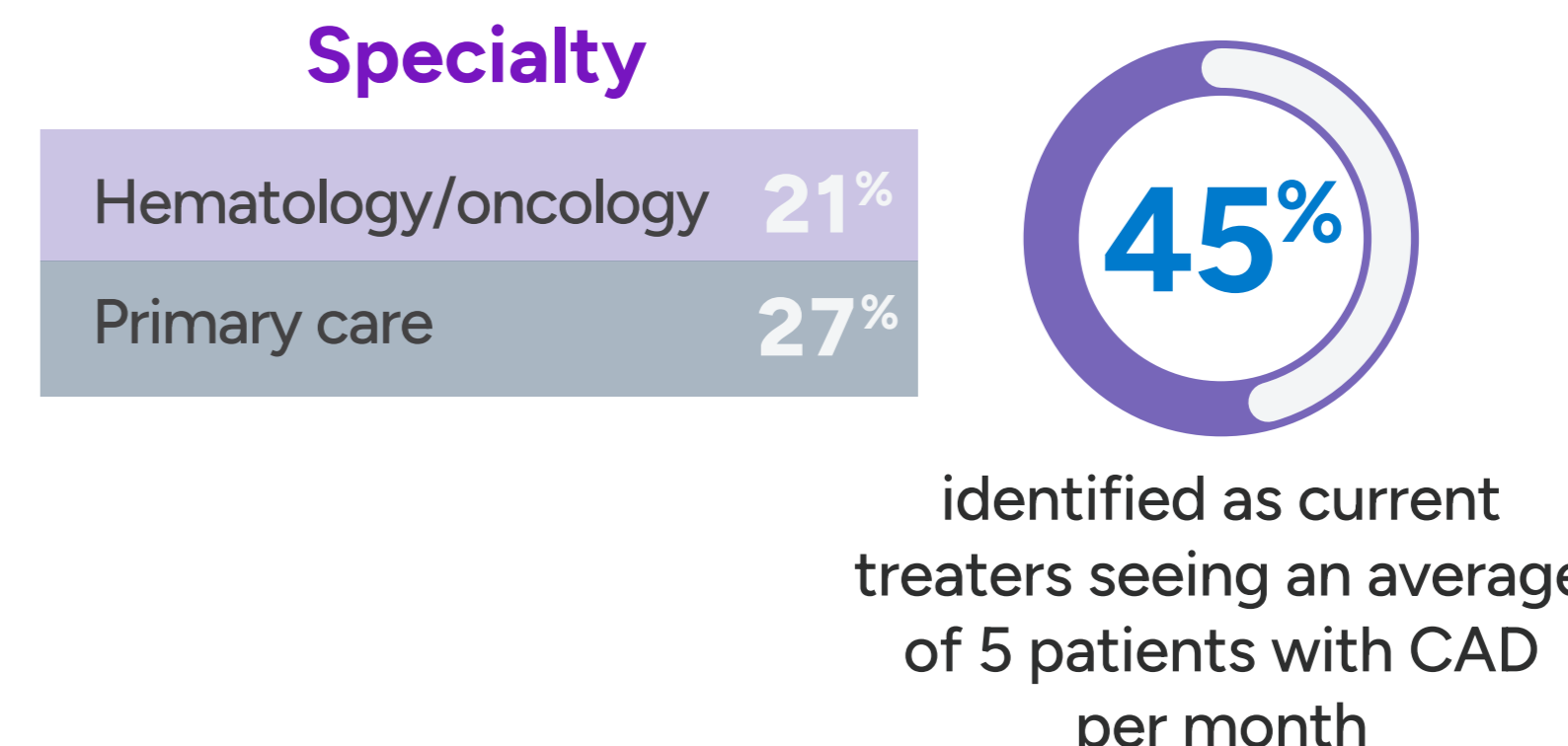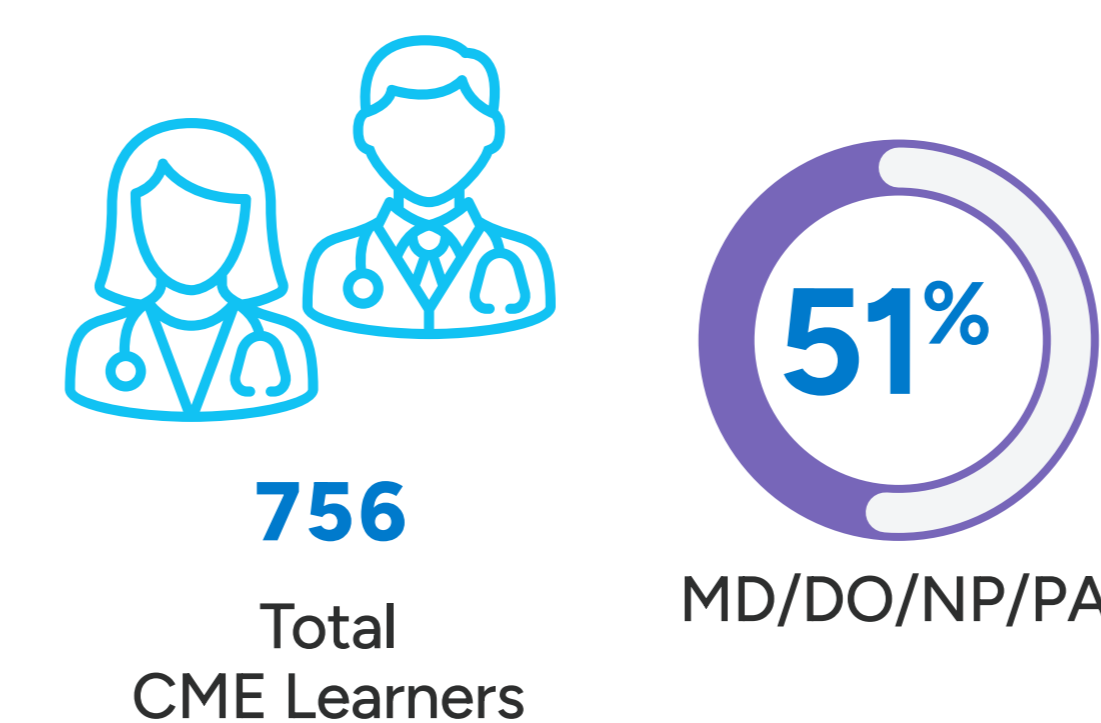
Measurements

Questions asked before and immediately after participating in an activity; 2-month follow-up survey. Chi-square tests were used for statistical analysis.
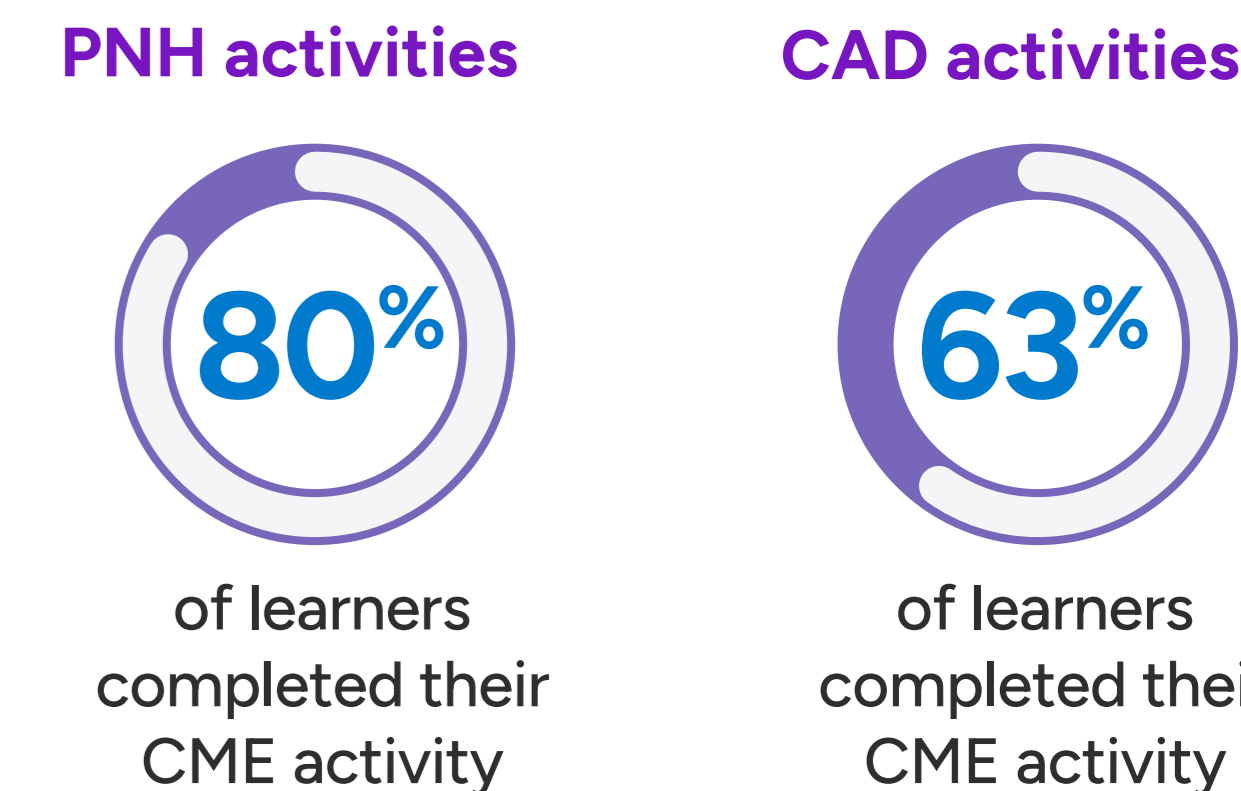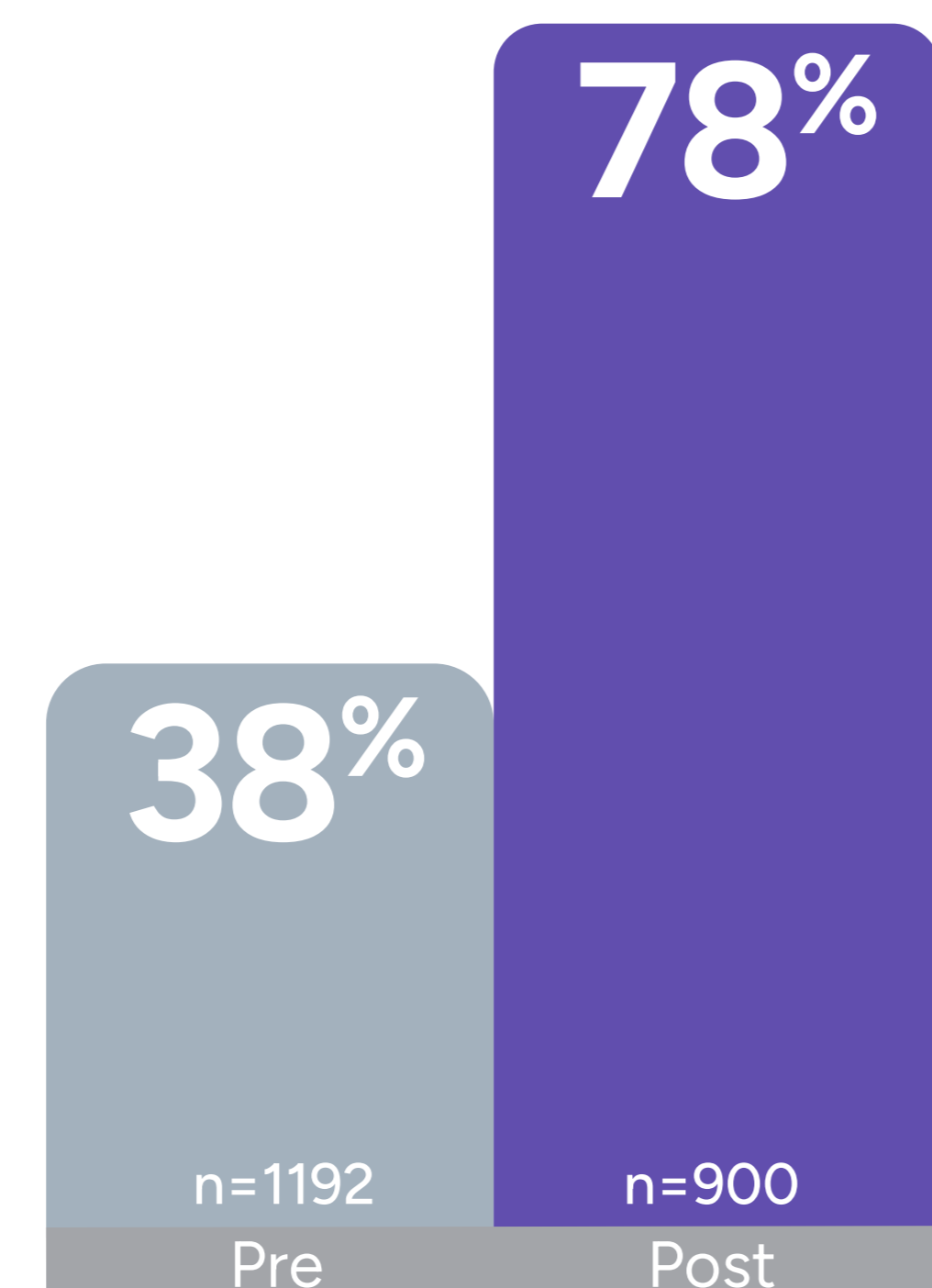
RESULTS

Learner Demographics (PNH activities)

2,528
Total Learners
(CME activities: 1,192; micro-learning activities: 1,336)

86% MD/DO/NP/PA

Specialty
Hematology/oncology — 45%
Primary care — 25%

41% identified as current treaters seeing an average of 5 patients with PNH per month

Learner Demographics (CAD activities)

756
Total CME Learners

51% MD/DO/NP/PA

Specialty
Hematology/oncology — 21%
Primary care — 27%

45% identified as current treaters seeing an average of 5 patients with CAD per month

Learner Engagement

PNH activities
80% of learners completed their CME activity

CAD activities
63% of learners completed their CME activity

Learning Gain

38% n=1192 Pre
78% n=900 Post

Average % correct on 3-item test linked to activity learning objectives for two PNH CME activities
*P*<0.05

30% n=756 Pre
57% n=474 Post
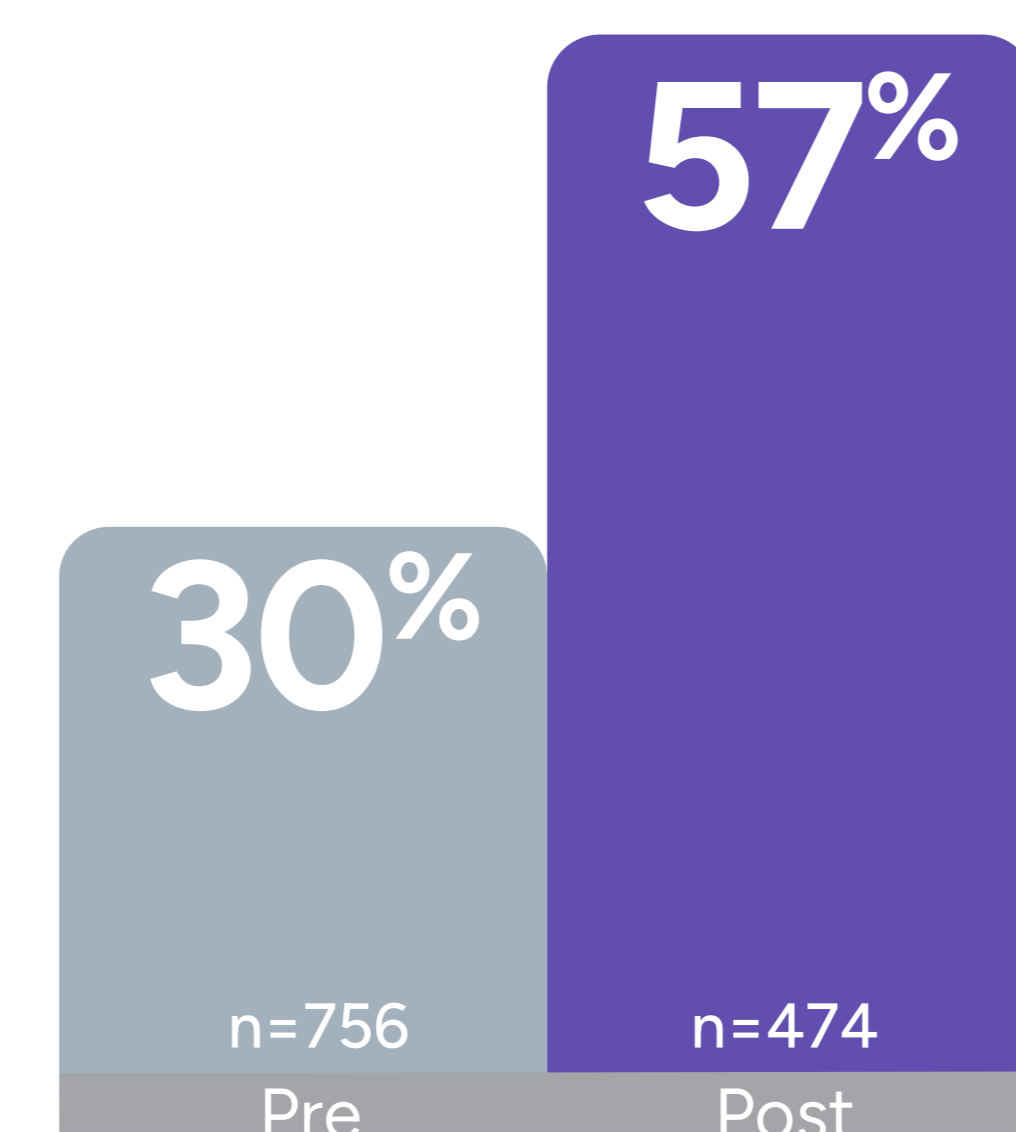
Average % correct on 3-item test linked to activity learning objectives for two CAD CME activities
P<0.05

Approximately three-quarters (77%) of learners in both the **PNH** and **CAD** CME activities reported an intention to change their practice based on their participation in the education.

At 2-month follow-up, >90% reported a positive impact on their clinical practice.

77%   **>90%**
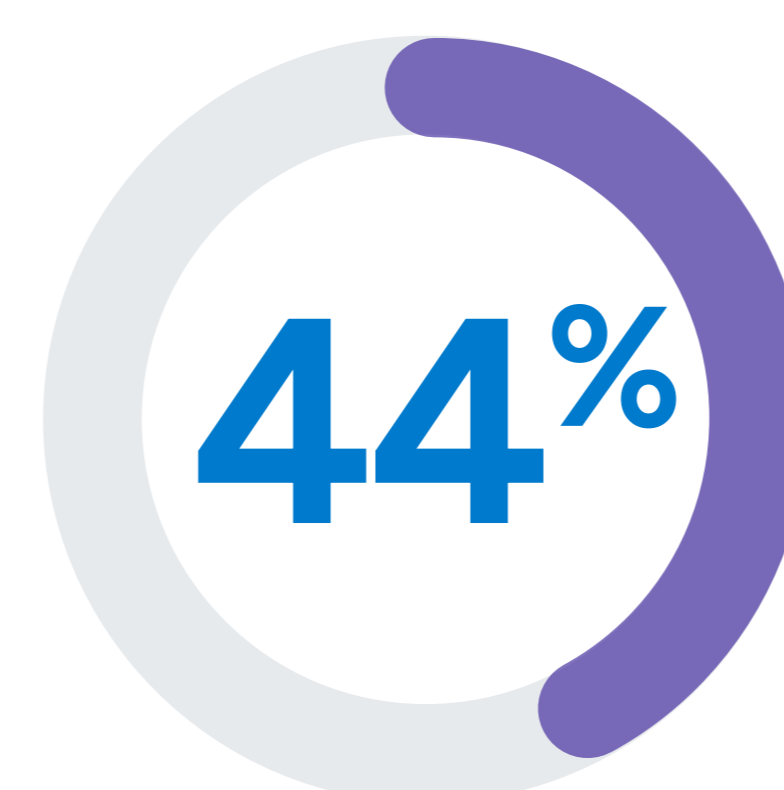
44% Nearly half (44%) of both **PNH** and **CAD** CME learners identified "lack of knowledge regarding evidence-based strategies" as the **top barrier to practice change**.

The second greatest barrier was "insurance, reimbursement, or legal issues" for **PNH** learners and "lack of time/resources to consider change" for **CAD** learners.
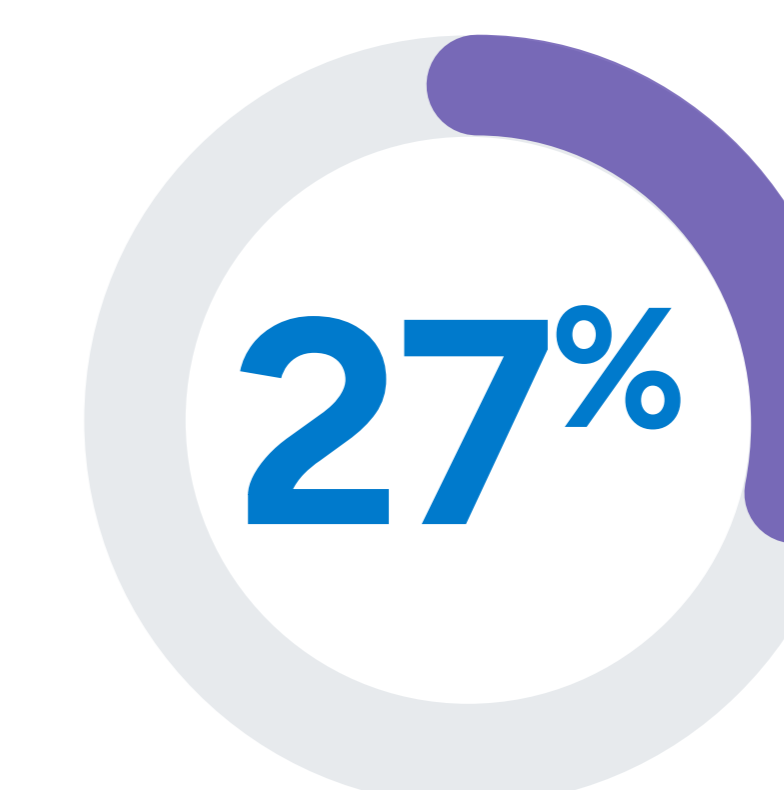
27% The **top management challenge** in PNH was "time to diagnosis" of patients (27%).

However, the **top management challenge** in CAD changed from "lack of novel therapies" (26%) in 2020 to "time to diagnosis" (27%) in 2022.

26% "lack of novel therapies"   **27%** "time to diagnosis"
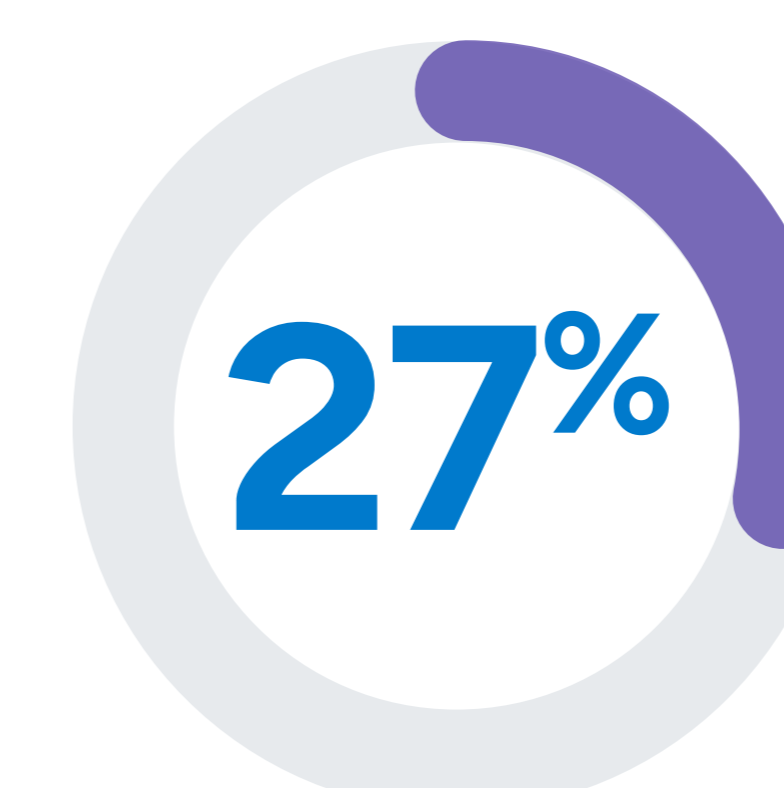
Most learners perceived "adhering to treatment schedules" as the greatest challenge faced by patients. Among **PNH** and **CAD** treaters, the major diagnostic roadblock was lack of familiarity with the clinical presentation of each disorder.

CONCLUSION

Online PNH and CAD education delivered between 2020 and 2023 increased clinician motivation to improve patient outcomes through the incorporation of new knowledge into clinical practice. However, outcomes from these educational initiatives also uncovered important challenges and barriers in practice. These insights necessitate ongoing clinician education and will inform the clinical strategies included in future initiatives.