

Workforce Workgroup: Reimagining the Workforce

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Arlington, Virginia



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Workforce Group Members



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Stanford University School of Medicine

Disclosures

Dr. Amy Shapiro

Consultative/Advisory Board: Novo Nordisk, Pfizer, Genentech, Kedrion, Sanofi

Dr. Lynn Malec

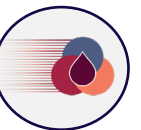
Consultative/Advisory Board: CSL Behring, Novo Nordisk, Sanofi, Sobi, Spark Therapeutics, Takeda



Core Recommendations



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Core Recommendations: Support Research within the MDT



HTC's support furtherance of evidence-based care for persons with bleeding disorders; EBC is founded upon research



Foster an HTC culture that is inclusive of advancing care through the national research agenda



MDT team job descriptions/core functions to include research participation: Seek HTC, Regional, National support for the use of program income for newly described duties

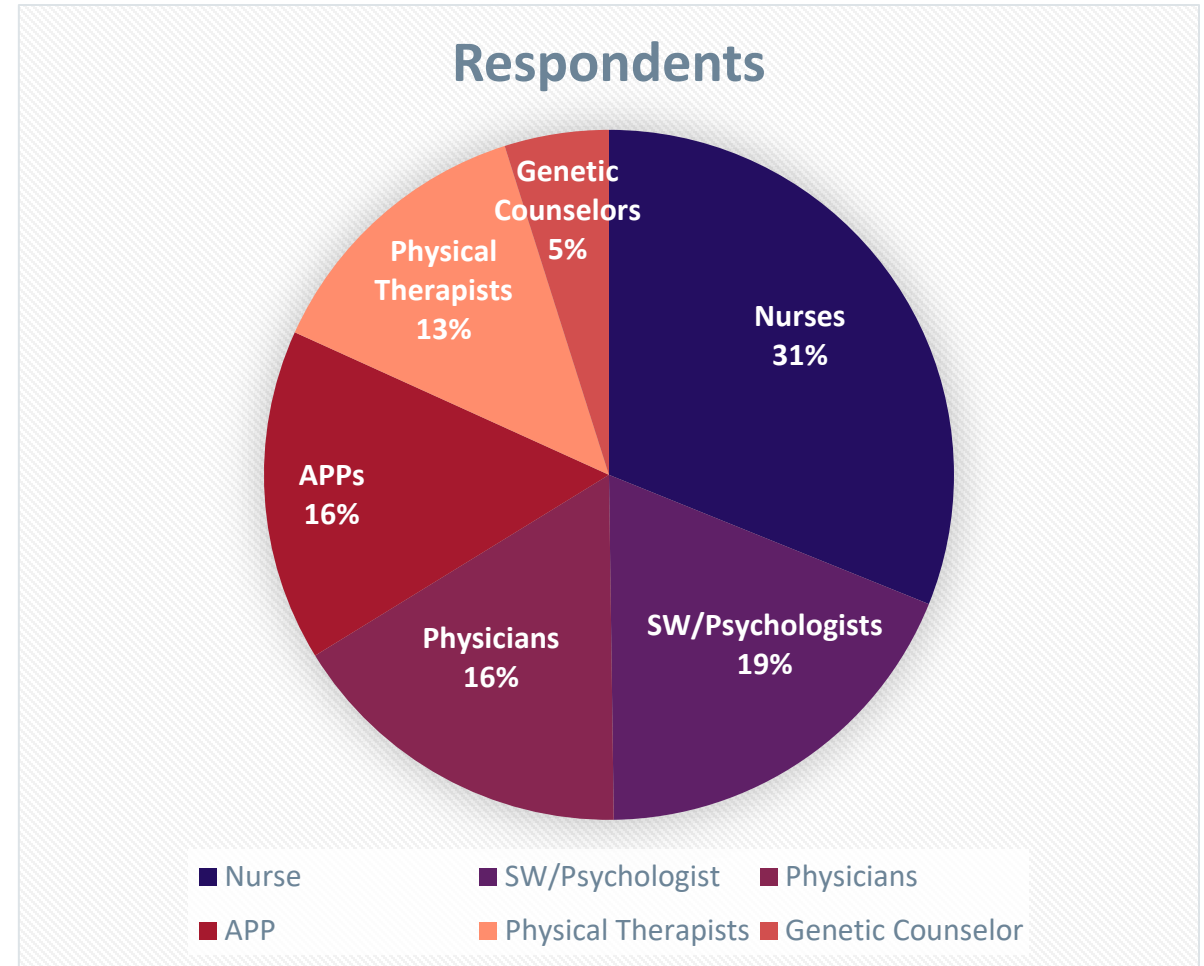


Promote participation in existing and/or develop new research educational programs for disciplines as required



Define Workforce Baselines

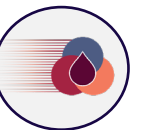
- National Workforce Survey of HTC staff – included full MDT
 - Knowledge of research
 - Capacity for participation
 - Current work/interface in research
 - Workforce demographic information to inform diversity of current staff
- Conducted with assistance of NHPCC
 - 02 Oct 2023 → 17 Dec 2023
 - 225 total responses



Knowledge of Research



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This is an area of research interest

Topic	Area of research interest						
	Genetic Counselor (n=6)	Physical Therapist (n=22)	Advanced Practice Provider (n=28)	Physician (n=32)	Psychologist, Social Worker (n=34)	Nurse (n=55)	ALL (n=177)
Basics of research	0%	23%	29%	31%	18%	38%	28%
Good Clinical Practice	0%	41%	36%	41%	26%	33%	33%
Protocol design and development	0%	23%	21%	41%	15%	24%	24%
Research Ethics	33%	14%	29%	41%	18%	33%	28%
Types of Research	0%	14%	25%	31%	15%	31%	24%
Clinical Trial Process	0%	9%	29%	31%	15%	31%	24%
Engaging underserved populations	33%	36%	43%	44%	53%	42%	44%
Recruitment Strategies	0%	9%	14%	38%	21%	27%	23%
Clinical trials	0%	23%	29%	63%	21%	35%	33%
Observational trials	17%	23%	36%	69%	18%	36%	36%
Health outcome studies	17%	41%	43%	53%	56%	40%	45%
Basic/translational research	0%	27%	25%	34%	18%	27%	25%
Clinical/translational	0%	36%	21%	56%	15%	29%	30%
Implementation science /trials	0%	14%	18%	34%	9%	24%	20%
Epidemiology	17%	9%	29%	31%	9%	33%	24%
Informatics	17%	9%	7%	19%	9%	29%	17%
Data Science	17%	9%	4%	9%	6%	24%	12%
Biostatistics	17%	9%	7%	6%	3%	18%	10%
Patient Centered Outcomes Research	33%	50%	43%	44%	41%	38%	42%
Health Services Research	17%	27%	18%	19%	21%	25%	22%
Health Economics Research	17%	9%	7%	16%	26%	25%	19%
Health Disparities Research	33%	23%	21%	38%	47%	31%	33%
Community Based Participatory Research	17%	23%	21%	13%	29%	22%	21%

I would like more knowledge on this topic

		Would like more knowledge on this topic						
pic		Genetic	Physical Therapist	Advanced	Physician	Psychologist,	Nurse	ALL
		Counselor (n=6)	(n=22)	Practice Provider (n=28)	(n=32)	Social Worker (n=34)	(n=55)	(n=177)
	Basics of research	50%	23%	32%	13%	47%	42%	34%
	Good Clinical Practice	33%	18%	36%	16%	50%	27%	30%
	Protocol design and development	50%	32%	43%	41%	41%	38%	40%
	Research Ethics	17%	32%	25%	16%	35%	36%	29%
	Types of Research	33%	32%	36%	22%	41%	33%	33%
	Clinical Trial Process	17%	41%	39%	22%	35%	33%	33%
	Engaging underserved populations	33%	32%	39%	31%	38%	40%	37%
	Recruitment Strategies	33%	32%	25%	22%	35%	38%	32%
	Clinical trials	17%	32%	29%	13%	29%	29%	26%
	Observational trials	17%	23%	25%	6%	29%	27%	23%
	Health outcome studies	33%	27%	32%	19%	35%	33%	30%
	Basic/translational research	33%	23%	18%	28%	35%	31%	28%
	Clinical/translational	33%	32%	21%	22%	29%	31%	28%
	Implementation science /trials	33%	27%	14%	25%	26%	25%	24%
	Epidemiology	50%	23%	32%	28%	32%	27%	29%
	Informatics	33%	18%	18%	34%	29%	27%	27%
	Data Science	50%	18%	14%	41%	29%	25%	27%
	Biostatistics	17%	23%	11%	47%	29%	27%	28%
	Patient Centered Outcomes Research	33%	32%	43%	28%	38%	42%	37%
	Health Services Research	33%	27%	32%	34%	29%	27%	30%
	Health Economics Research	33%	27%	18%	38%	38%	24%	29%
	Health Disparities Research	33%	36%	32%	38%	38%	29%	34%
	Community Based Participatory Research	33%	36%	32%	38%	35%	25%	32%

I would like more training on this topic

Topic	Would like more training on this topic						
	Genetic Counselor (n=6)	Physical Therapist (n=22)	Advanced Practice Provider (n=28)	Physician (n=32)	Psychologist, Social Worker (n=34)	Nurse (n=55)	ALL (n=177)
Basics of research	0%	32%	21%	9%	35%	24%	28%
Good Clinical Practice	0%	32%	25%	6%	29%	18%	33%
Protocol design and development	0%	27%	46%	25%	29%	16%	24%
Research Ethics	0%	18%	11%	9%	26%	11%	28%
Types of Research	0%	27%	21%	0%	26%	13%	24%
Clinical Trial Process	0%	32%	25%	22%	18%	13%	24%
Engaging underserved populations	17%	23%	39%	25%	26%	22%	44%
Recruitment Strategies	0%	18%	18%	16%	21%	13%	23%
Clinical trials	17%	23%	21%	16%	12%	15%	33%
Observational trials	0%	18%	25%	9%	18%	16%	36%
Health outcome studies	17%	32%	36%	22%	26%	18%	45%
Basic/translational research	17%	23%	18%	9%	24%	16%	25%
Clinical/translational	17%	27%	25%	16%	21%	9%	30%
Implementation science /trials	17%	18%	32%	16%	21%	7%	20%
Epidemiology	17%	14%	32%	16%	12%	11%	24%
Informatics	33%	18%	21%	34%	21%	13%	17%
Data Science	17%	18%	14%	28%	21%	9%	12%
Biostatistics	50%	18%	14%	38%	26%	13%	10%
Patient Centered Outcomes Research	17%	41%	36%	19%	35%	16%	42%
Health Services Research	17%	23%	25%	13%	29%	11%	22%
Health Economics Research	17%	9%	21%	13%	26%	9%	19%
Health Disparities Research	17%	23%	29%	19%	38%	18%	33%
Community Based Participatory Research	17%	18%	29%	13%	32%	9%	21%

Capacity for Participation in Research

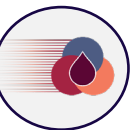
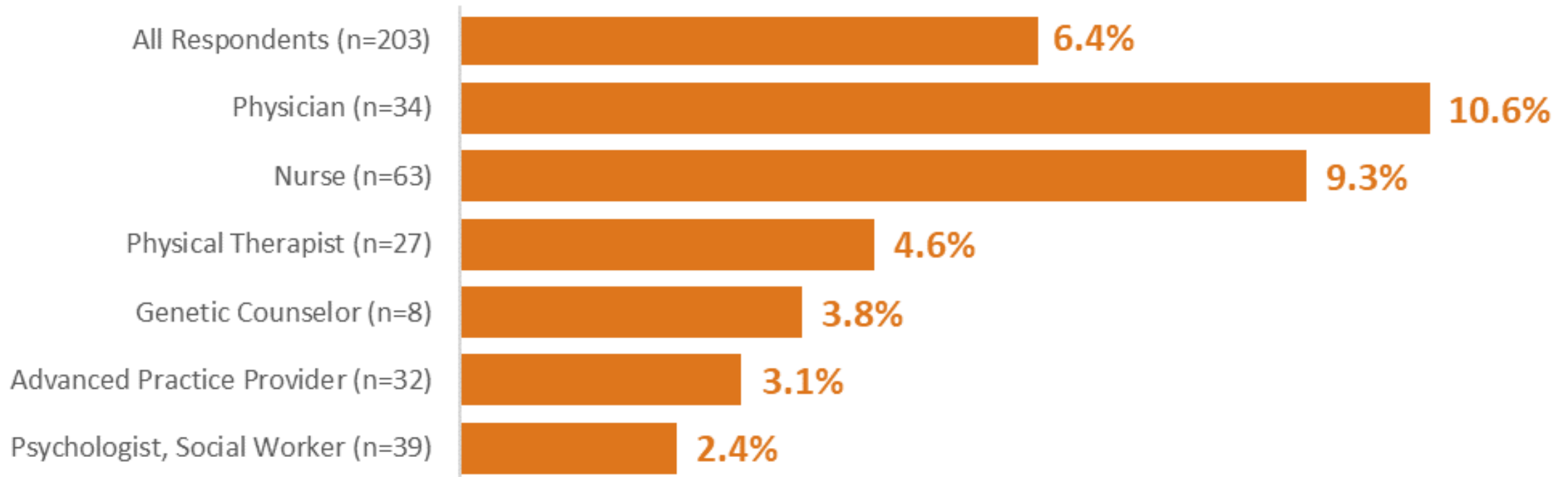


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Capacity for Participation in Research

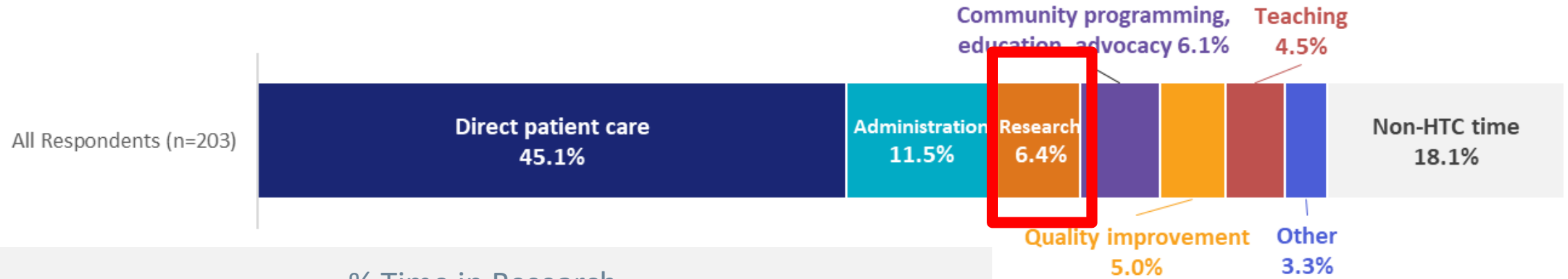
Q58. What percentage of your time is spent on the following areas? – HTC Research



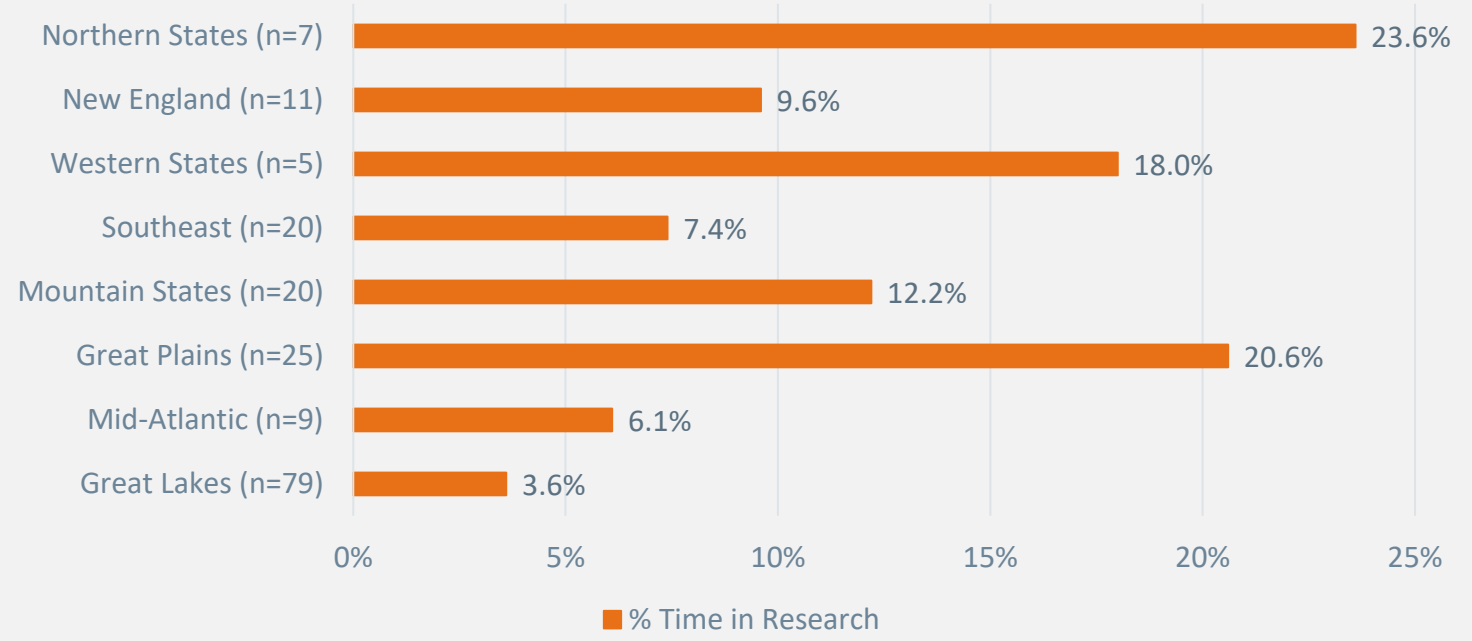
Percentage of time spent on HTC and non-HTC activities

Time Budget

Q58. What percentage of your time is spent on the following areas?



% Time in Research



Average percentage of time spent in each activity. All activities listed are HTC-related unless noted otherwise.

Barriers to Participation

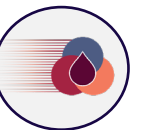
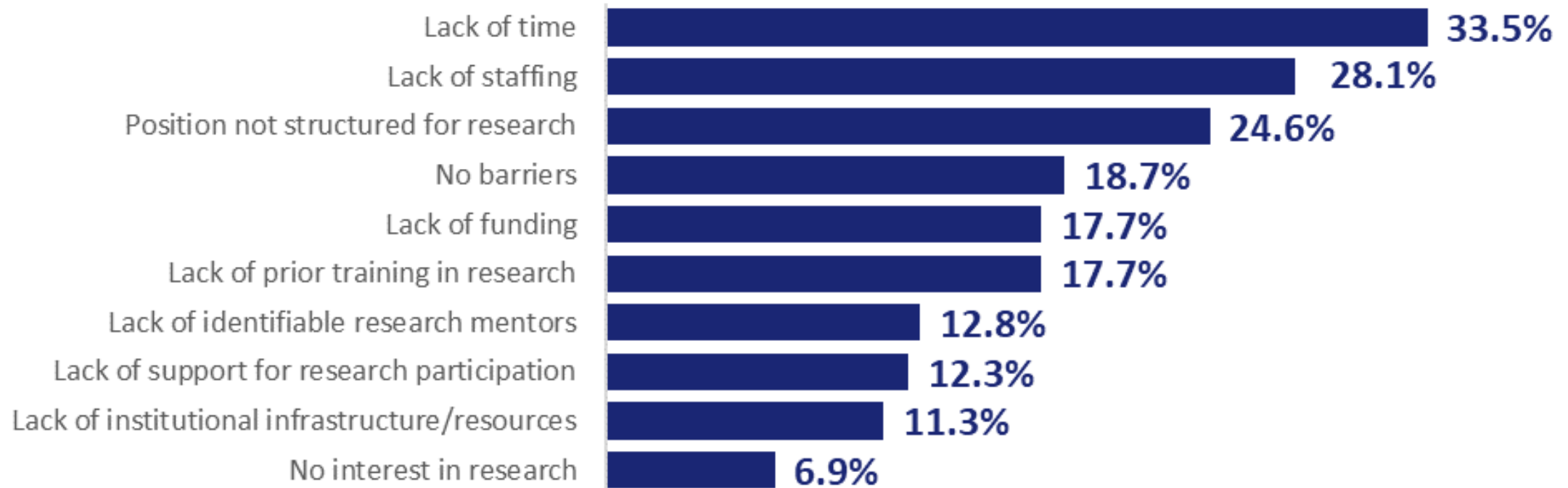


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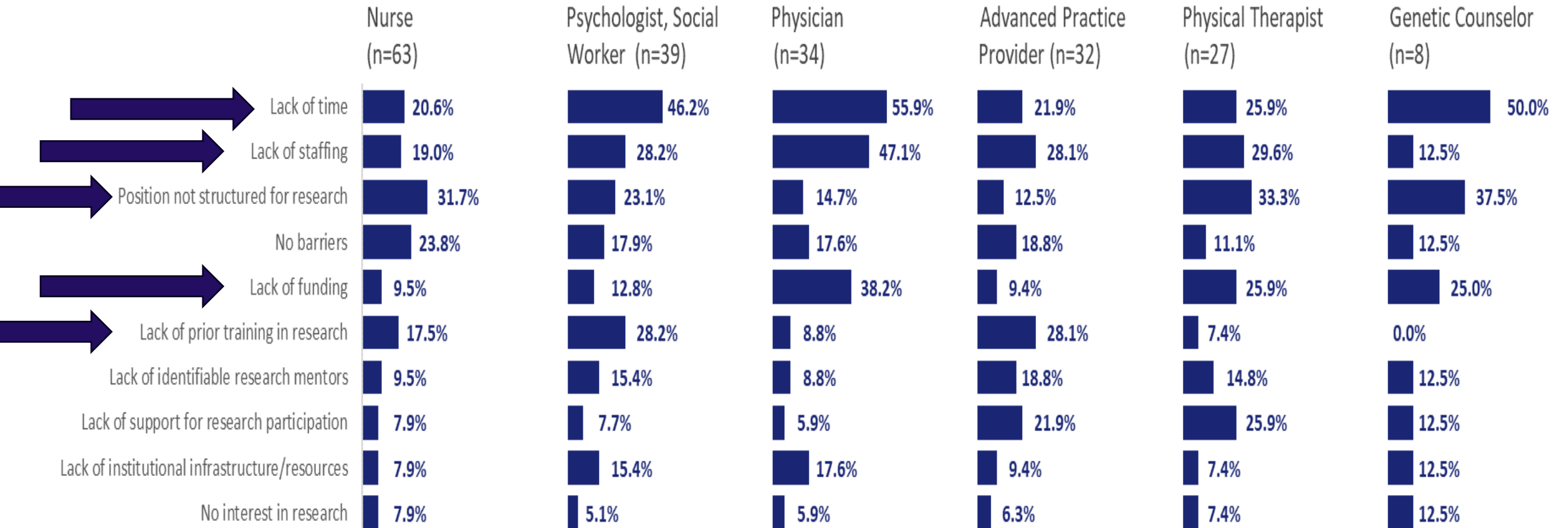


Barriers to Research

q10. Please check any barriers that you experience related to participating in clinical research.



Barriers to Research by Discipline



Core Recommendations: Support LEEs Participation in Research



Recognition of core role of LEEs in development of research protocols



Research Ambassadors support community understanding and knowledge of importance of participation in research endeavors



Develop core set of research education/training to support LEEs understanding of research process and allow substantive input based upon lived experience and research knowledge



Develop protocol/program specific training



Core Recommendations: Increase HTC-MDT Team Diversity



Work with local, state, national resources to develop/encourage novel programs to promote/increase diversity within the HTC MDT



Collaborate with HBCUs and other institutions dedicated to underrepresented communities (e.g., SEARCH Workshop)

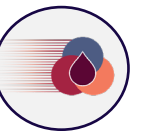


Identify mechanisms to obtain accurate data regarding diversity within the HTC MDT team



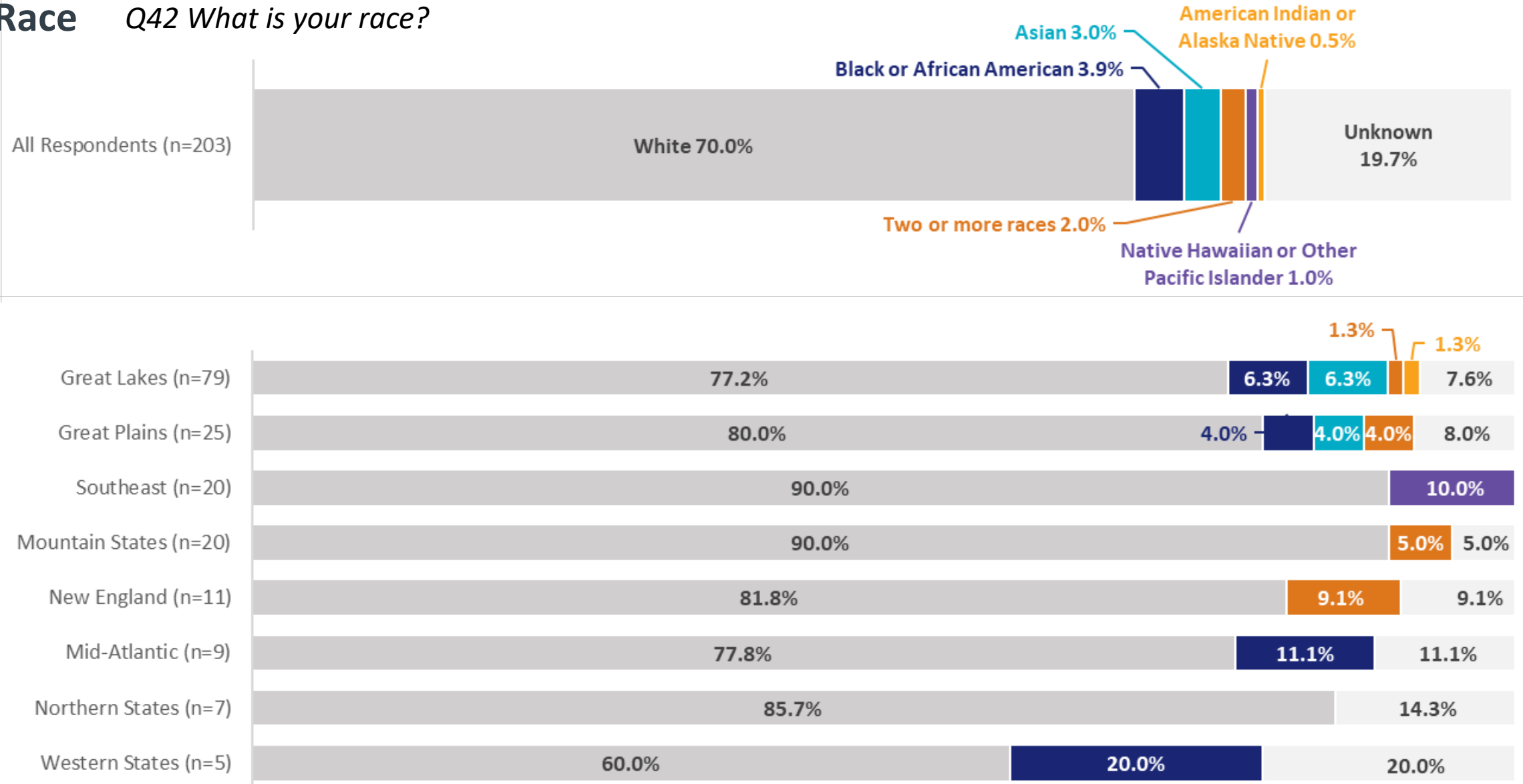


Diversity Data from Survey



Percentage of respondents by region

Race Q42 What is your race?

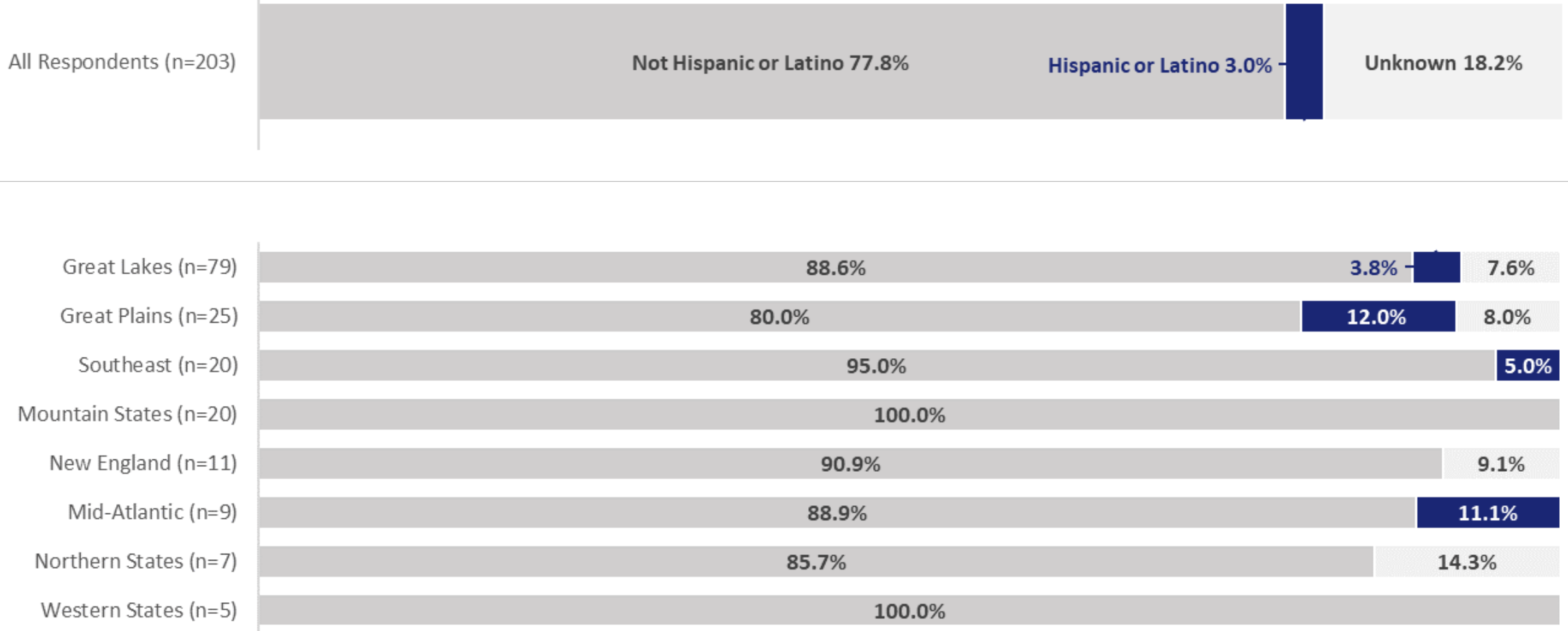


Note: "Unknown" includes those who marked "Prefer not to answer" and those who did not respond to this question.

Percentage of respondents by region

Ethnicity

Q43 What is your ethnicity?



Note: "Unknown" includes those who marked "Prefer not to answer" and those who did not respond to this question.

How Workforce Recommendations Harmonize with Other WGs



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Workforce Harmonization

Optimize workforce through use of 340b funds once approved

LEEs

Development of

1. Research Ambassador Program
2. Education to support LEEs & Research Ambassadors

Policy

Community Engagement

Work through LEEs and Research Ambassadors to support community engagement

HEDI

1. Increase workforce diversity
2. HEDI training program for broad use
3. MDT position templates include research

R & D

Support

1. Education across all disciplines
2. Broad core research principles education & training tailored to execute R&D priority agenda
3. Protocol specific training
4. Education & inclusion of LEEs at all levels of protocol development & process to increase trust/engagement within LEE community

Infrastructure

Create a centralized registry of research and training opportunities, grants, mentorships; integrate into NRB website



How these recommendations are Integrated into the proposed NRB Schema



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Building Engagement

- Alignment to build engagement and motivate existing and new partners to ensure NRB success
 - Inform partners that their engagement is desired from beginning
 - Be clear about partner's role given they may have other community positions
 - Identify and discuss perceived partner barriers/concerns to develop understanding early in process
 - Identify and highlight different motivational factors
 - Identify significant trust gaps within process to promote strategizing methods to overcome distrust , improve engagement opportunities
 - Develop specific strategies for specific partners
 - Identify, understand, and anticipate areas of friction to address them proactively



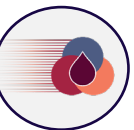
LEEs in Research Process

- Paradigm of how LEEs are considered part of research process requires reconfiguration
 - LEEs should be considered as part of the workforce and appropriately compensated for their time and work
 - Include standardized mechanism and incorporate in budgetary process
 - Website portal for NRB engagement of LEEs and HEDI champions, complimented by pathways to orient, educate, and engage interested participants in NRB processes and in outreach efforts as research ambassadors
 - Level NRB playing field
 - Require all participants to complete "boot camp-like" training program regardless of background and include HEDI education
 - Foster culture of collaboration, transparency, and authenticity



Potential Platforms for Education and Training

- Potential consideration for use of existing educational platforms such as PartnersPRN for MDT/LEE education
 - Continuing education credits could be offered for educational modules
 - Operating procedures are in place for content development
 - Specific content, curriculum, and speakers require determination
- CITI and other standardized research education programming are available through institutions
- Evaluate synergies with NBDF and HTRS
- NRB Cross-cutting committees to train and mentor investigators and ‘meet them where they are’



Potential Platforms for LEE Education and Training

- Potential consideration for use of existing platforms such as the NBDF website for LEE & Research Ambassador education
 - Access PCORI and/or Bureau of Sages Research Ambassador training content: Potential to link through NBDF website if feasible
 - Development of onboarding and retention procedures would be necessary
 - Certificates of completion could be offered
- Determine how to make CITI and other standardized research education programming available through centralized resource
- Develop protocol specific training for each research study housed on NRB website
- NRB Cross-cutting committees to train and mentor investigators and ‘meet them where they are’



Brief Questions and Answers

Thank you for your attention and to the
NHPCC for their work on the national survey
Workforce team members for time and contributions



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