

Open Comment Period Results

Electronic Survey

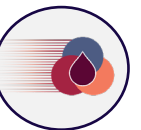
November 1 to December 15

Supporting materials

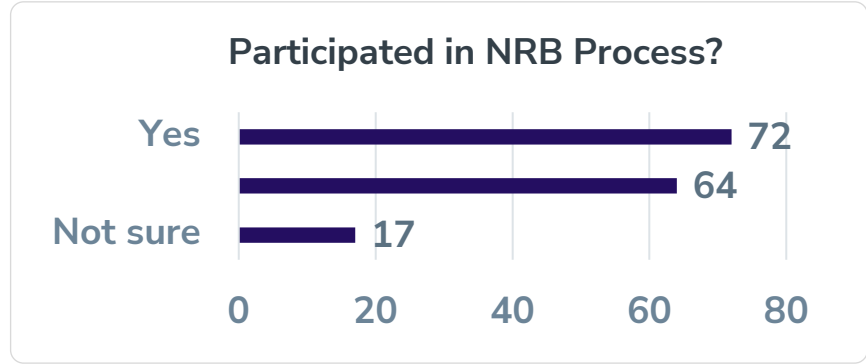
- Recorded Wednesday Webinar
- Global Hemophilia Report



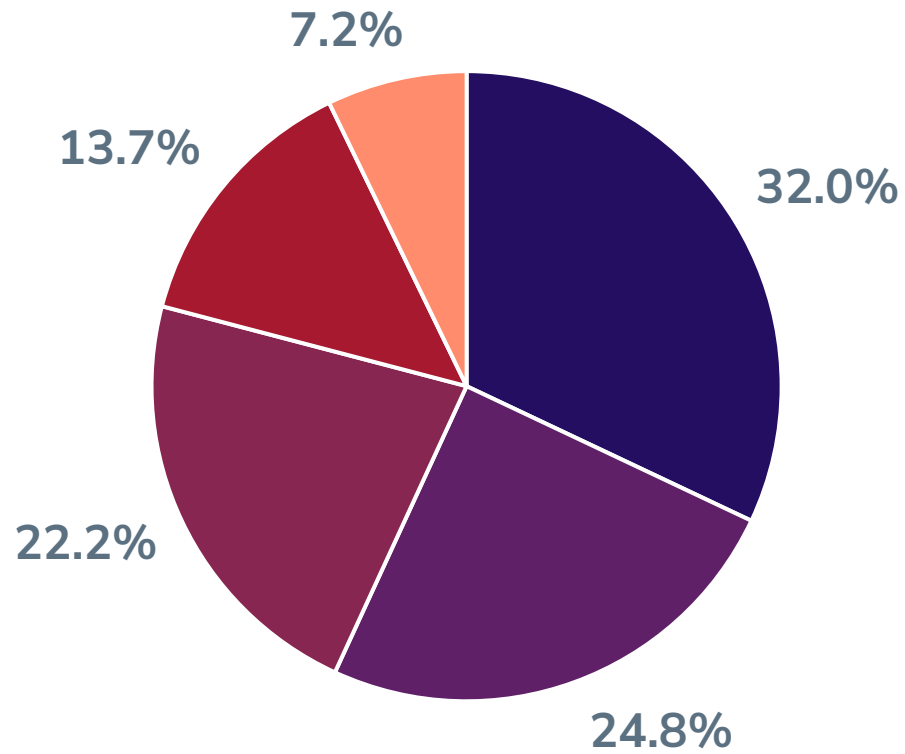
NATIONAL
BLEEDING DISORDERS
FOUNDATION
Formerly NHF



Open Comment Period Results



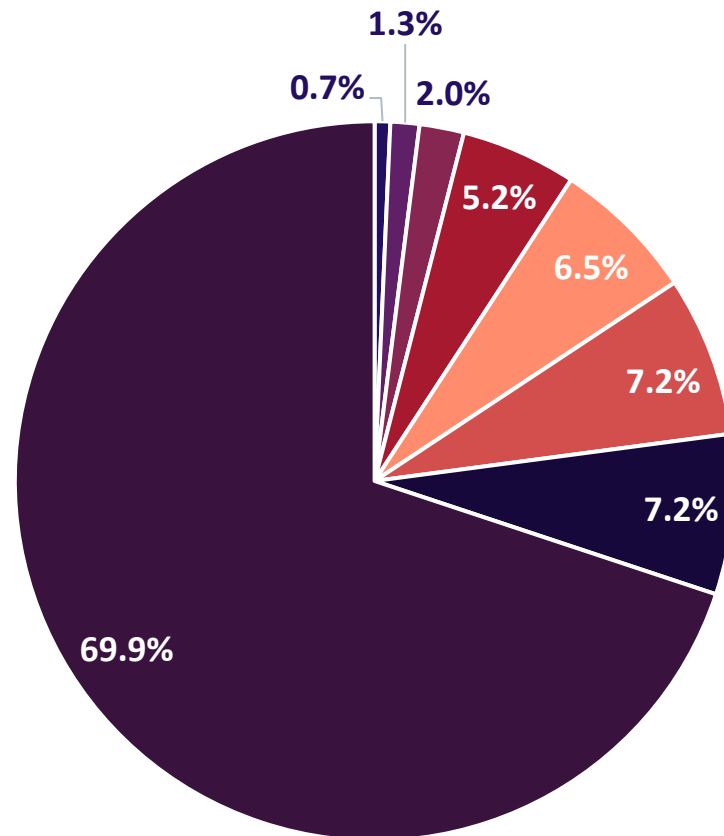
- LEE
- Allied Professionals
- Physician & Researchers
- Government & Non-profits
- Industry



Open Comment Period Results

Race

- White (n=107)
- DK/prefer not to answer (n=11)
- Black and/or African American (n=11)
- Asian (n=10)
- South Asian (n=8)
- Middle Eastern or North African (n=3)
- Asian, White (n=2)
- Asian, South Asian (n=1)



N = 153

Ethnicity

84.3%
Non-Hispanic
(n=129)

10.5%
Hispanic
(n=16)

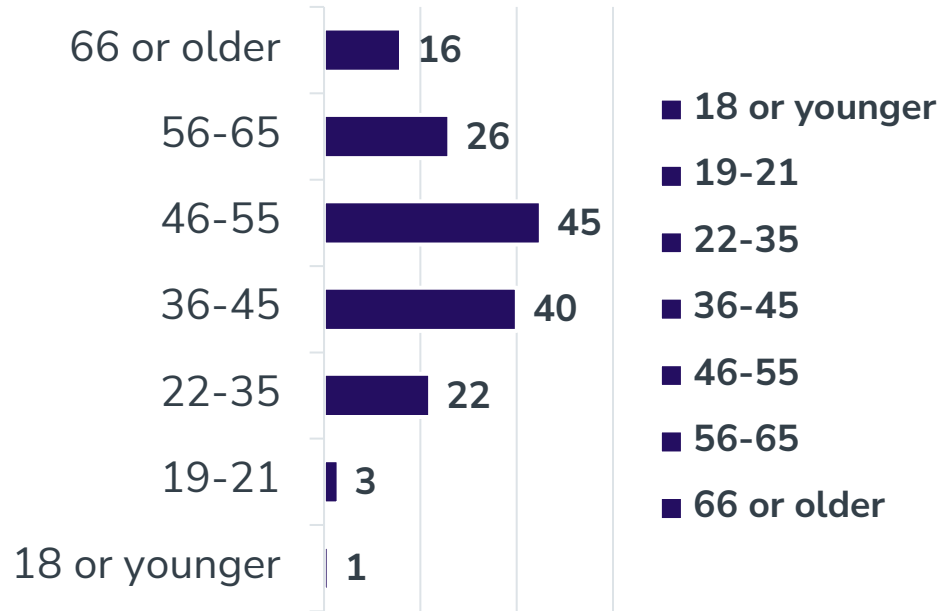
5.2%
Don't know/
Prefer not to
answer
(n=8)

N = 153



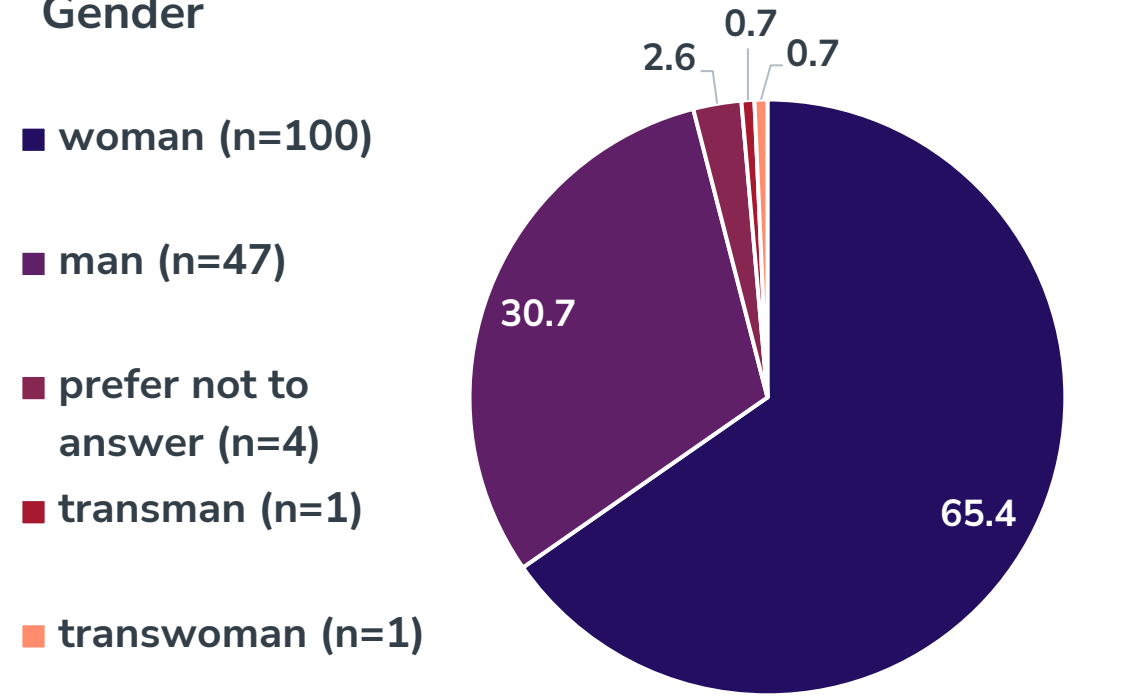
Open Comment Period Results

Age



N = 153

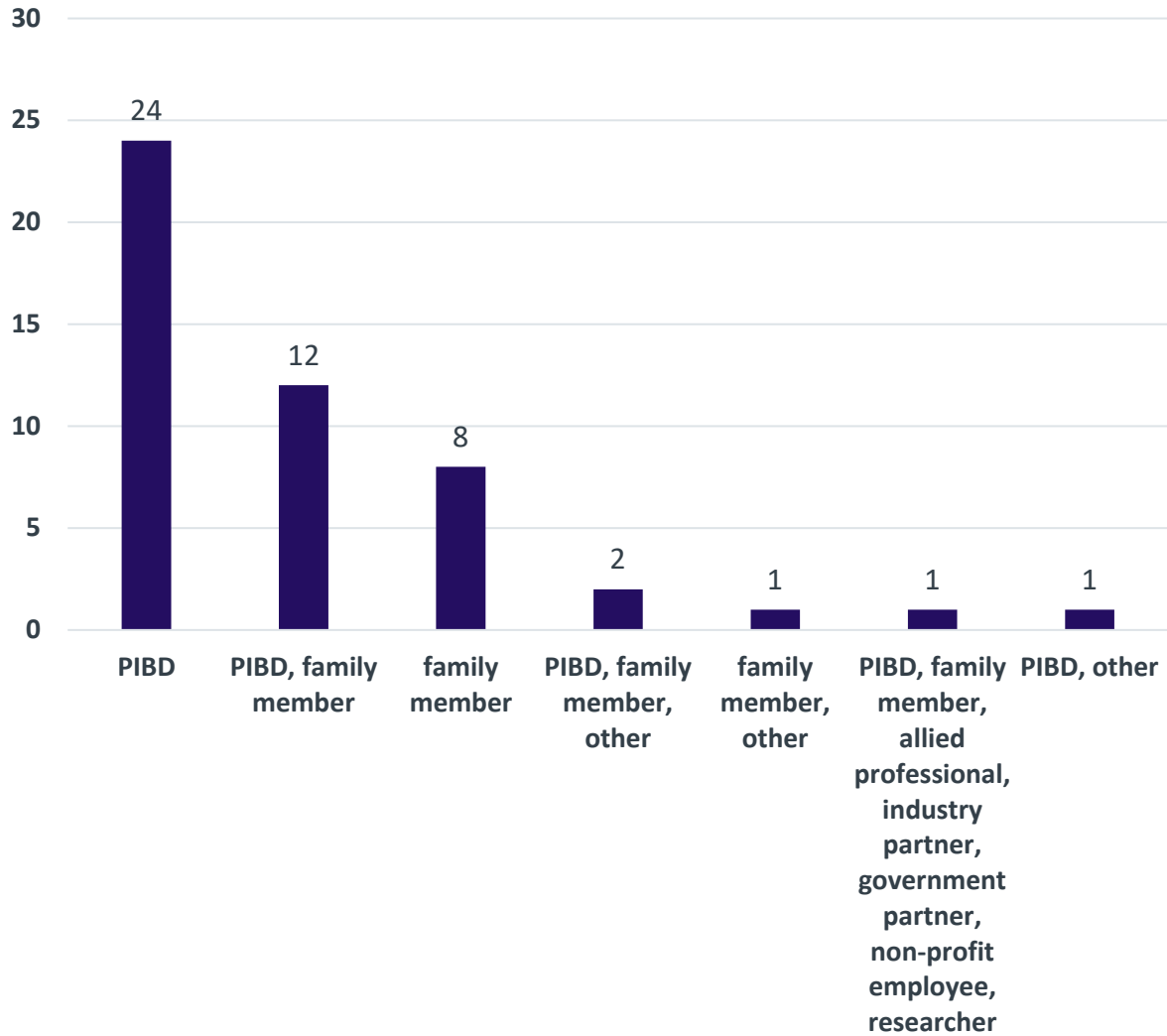
Gender



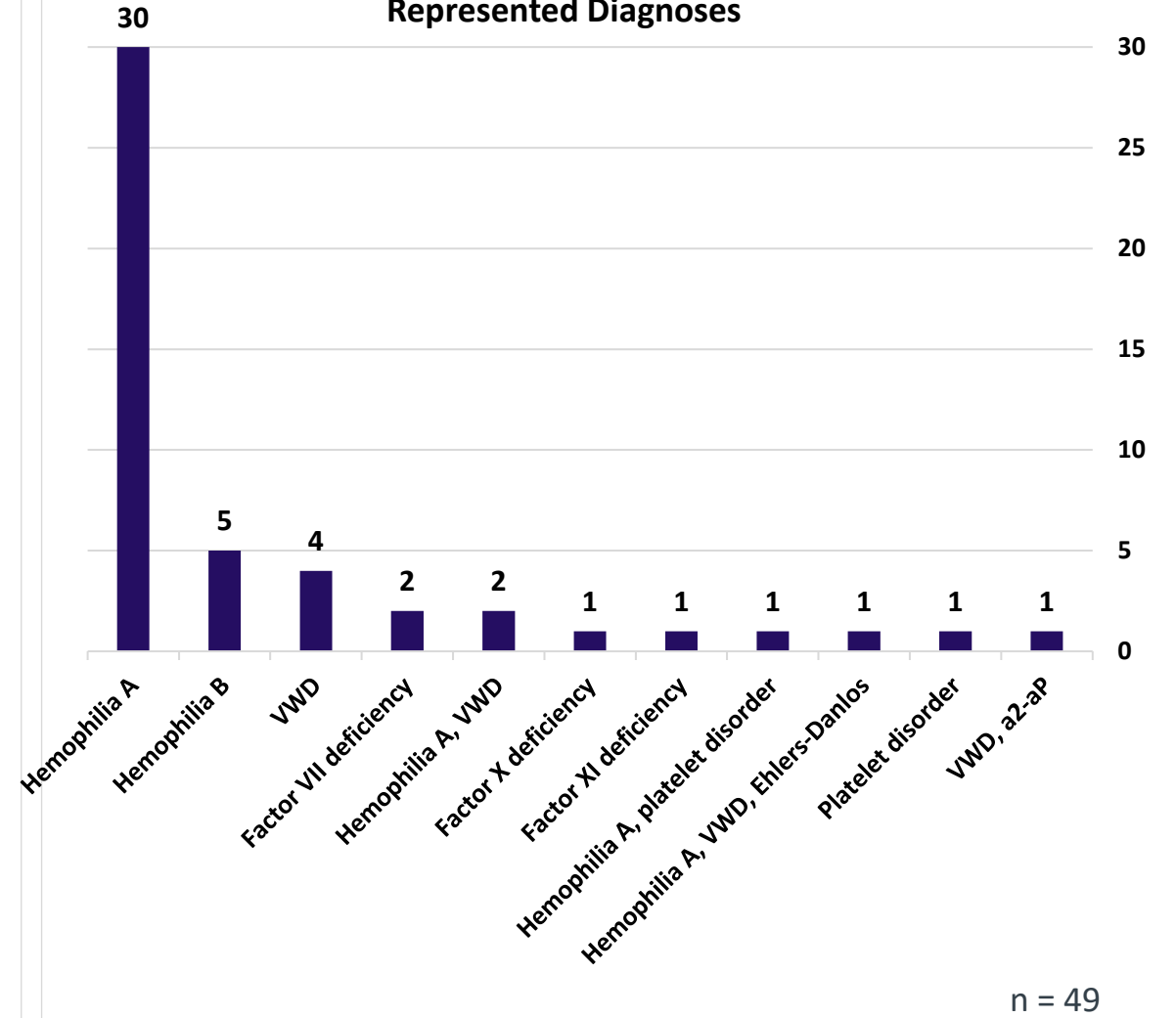
N = 153



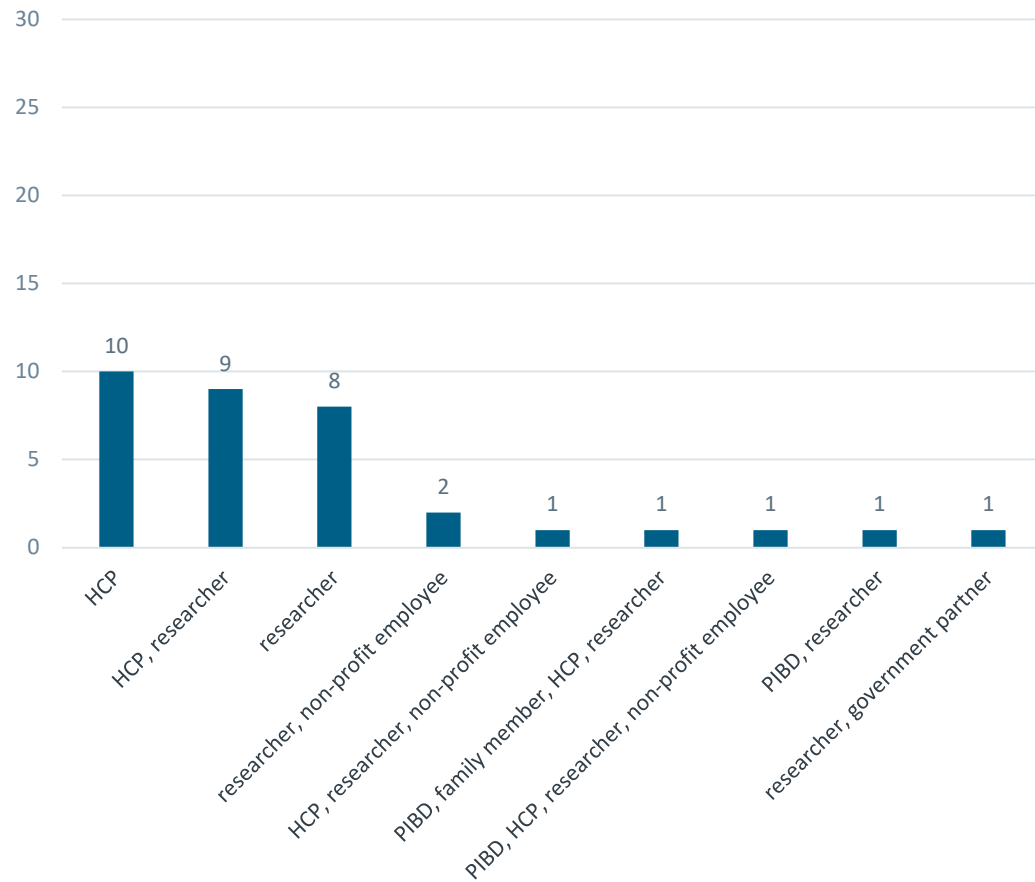
LEEs (n=49)



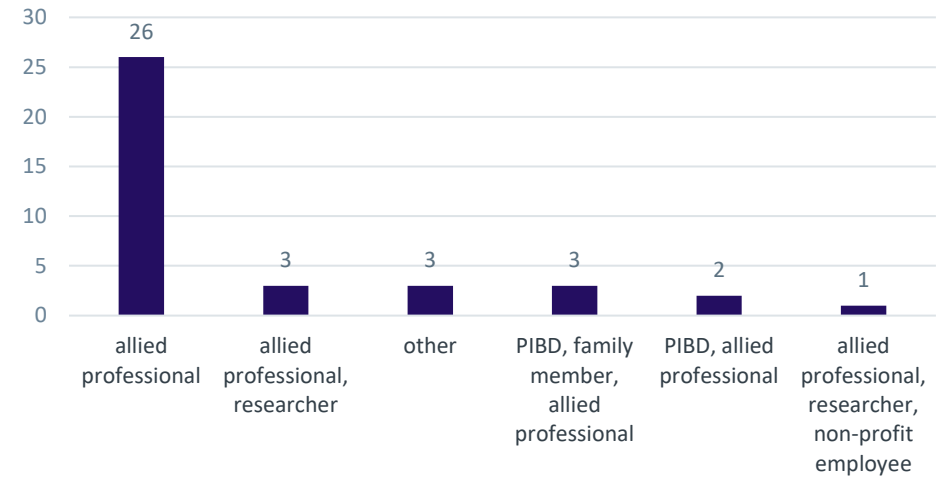
Represented Diagnoses



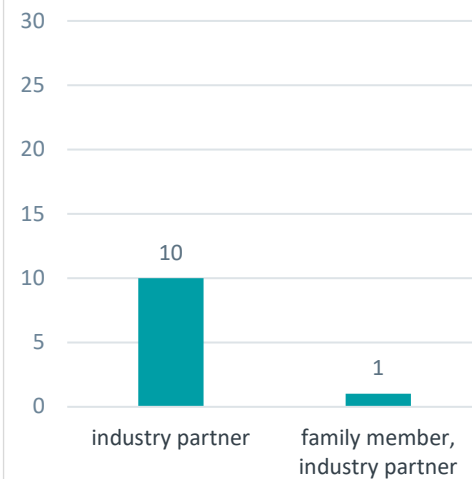
Physicians & researchers (n=34)



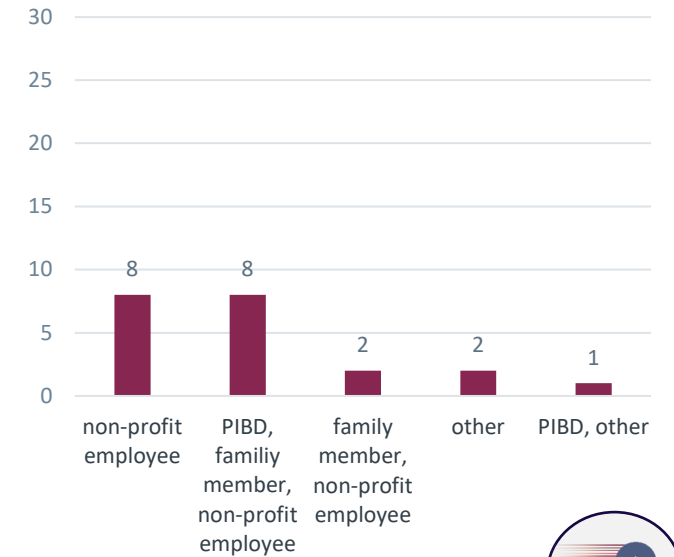
Allied professionals (n=38)



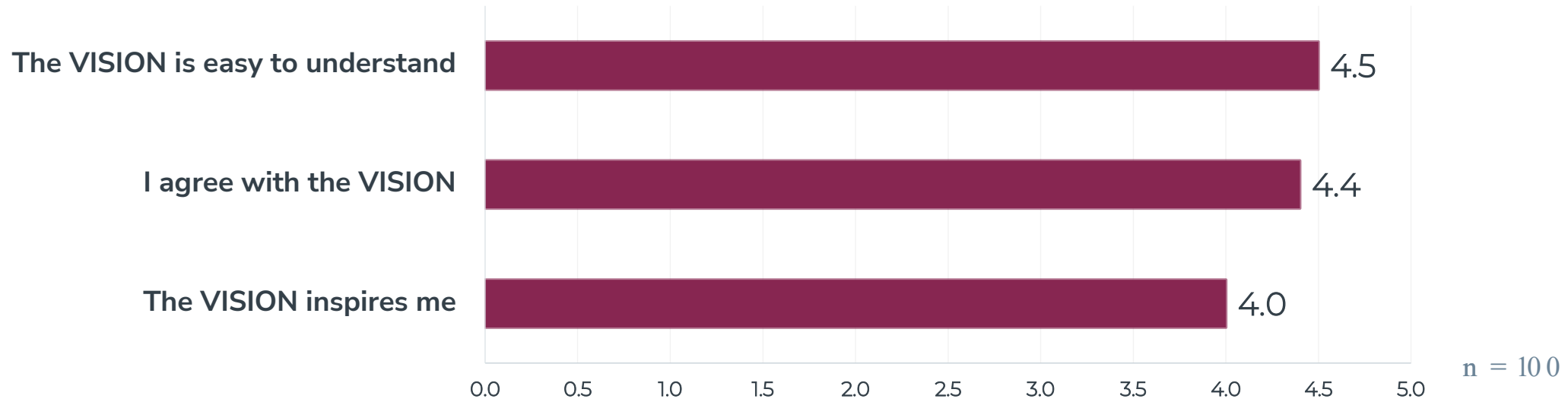
Industry partner (n=11)



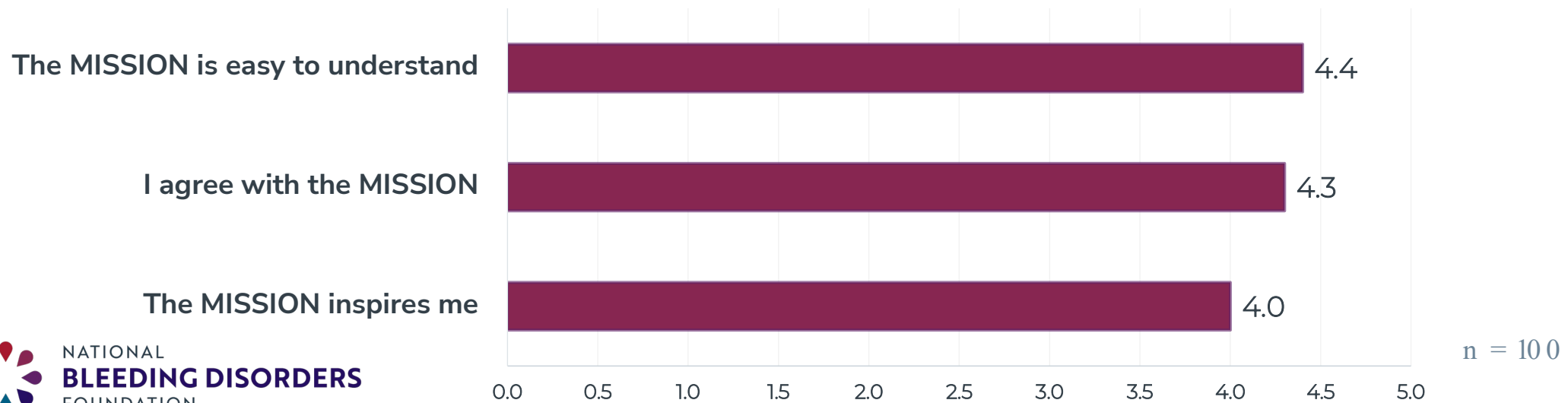
Government & non-profit (n=21)



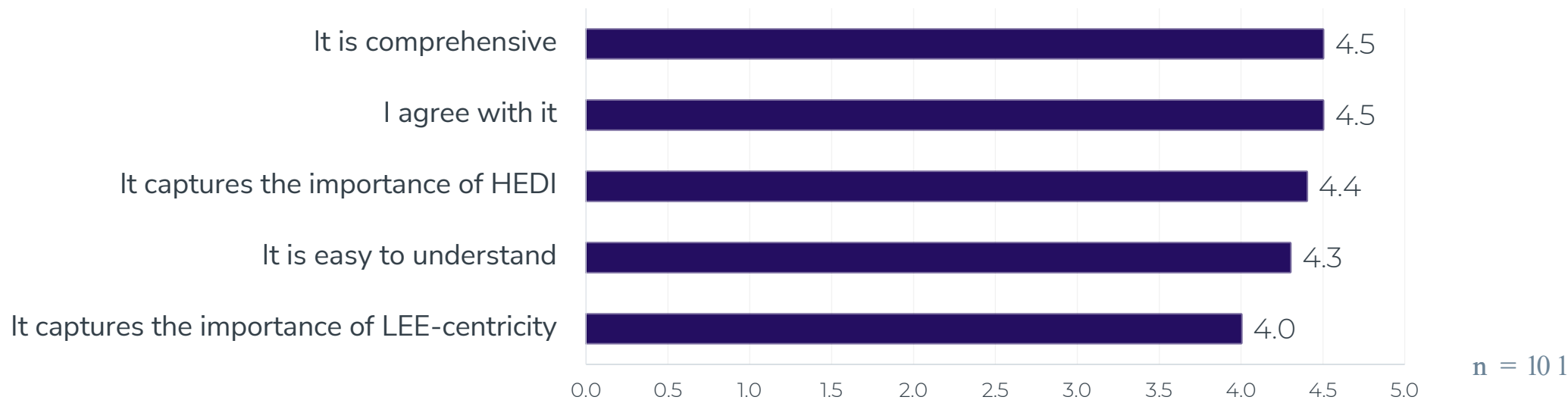
Vision



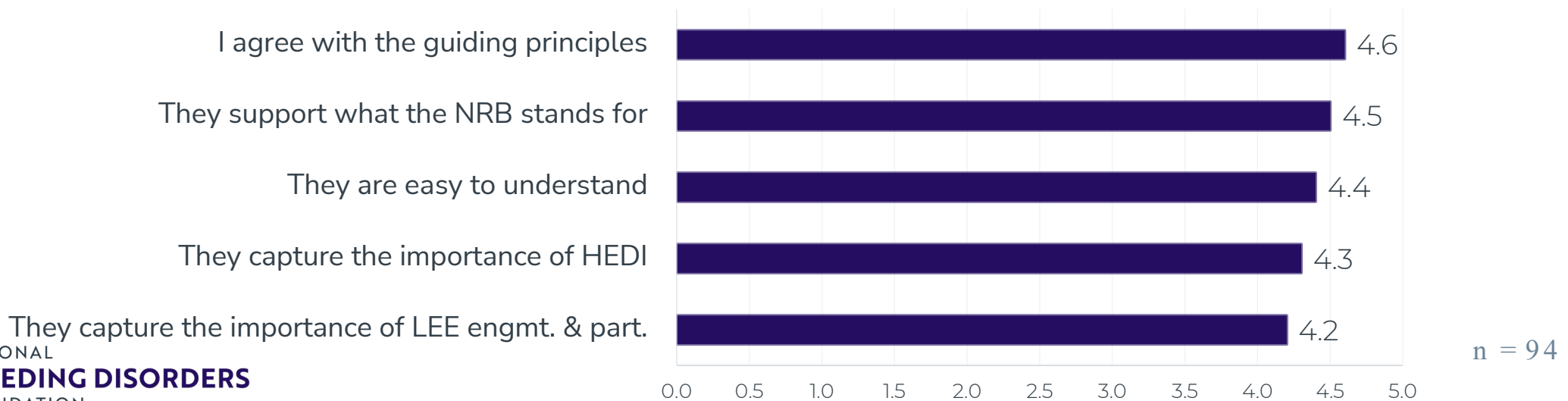
Mission



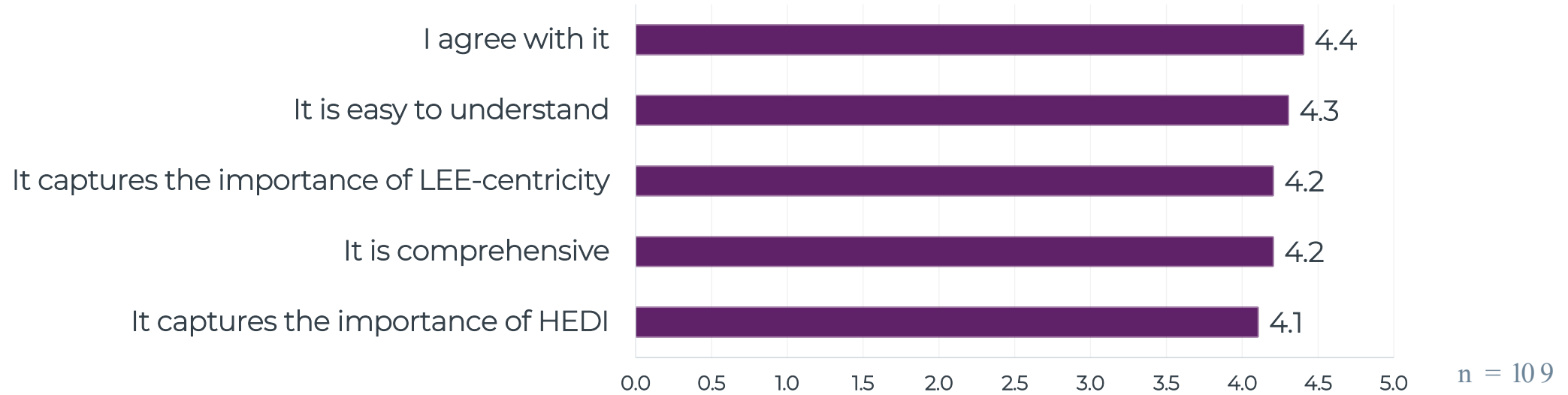
HEDI value statement



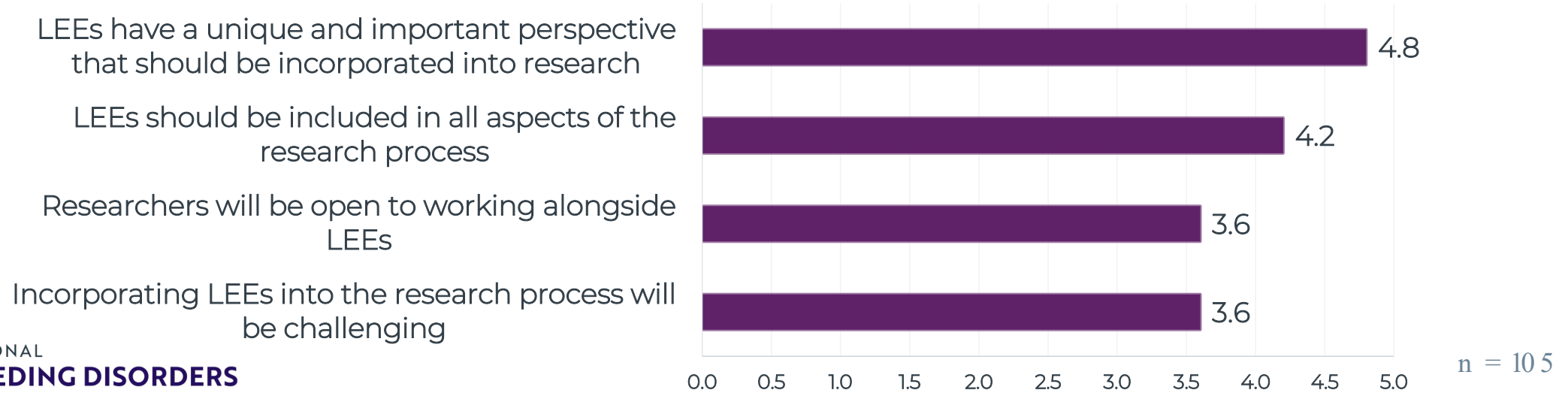
Guiding Principles



LEE Definition



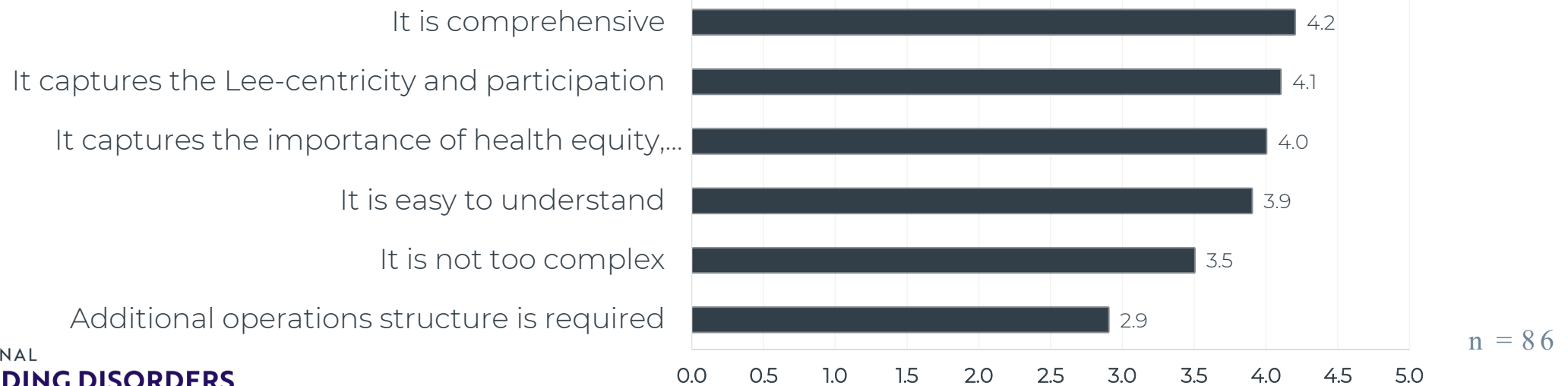
LEE Engagement and Participation



Governance Structure



Operations Structure



The National Research Blueprint and the Community

Based on the NRB Vision & Mission, how important will the NRB be to improving the standard of care for all persons affected by inherited...

How well do the proposed oversight and operational plans embody the LEE role in the NRB as defined?

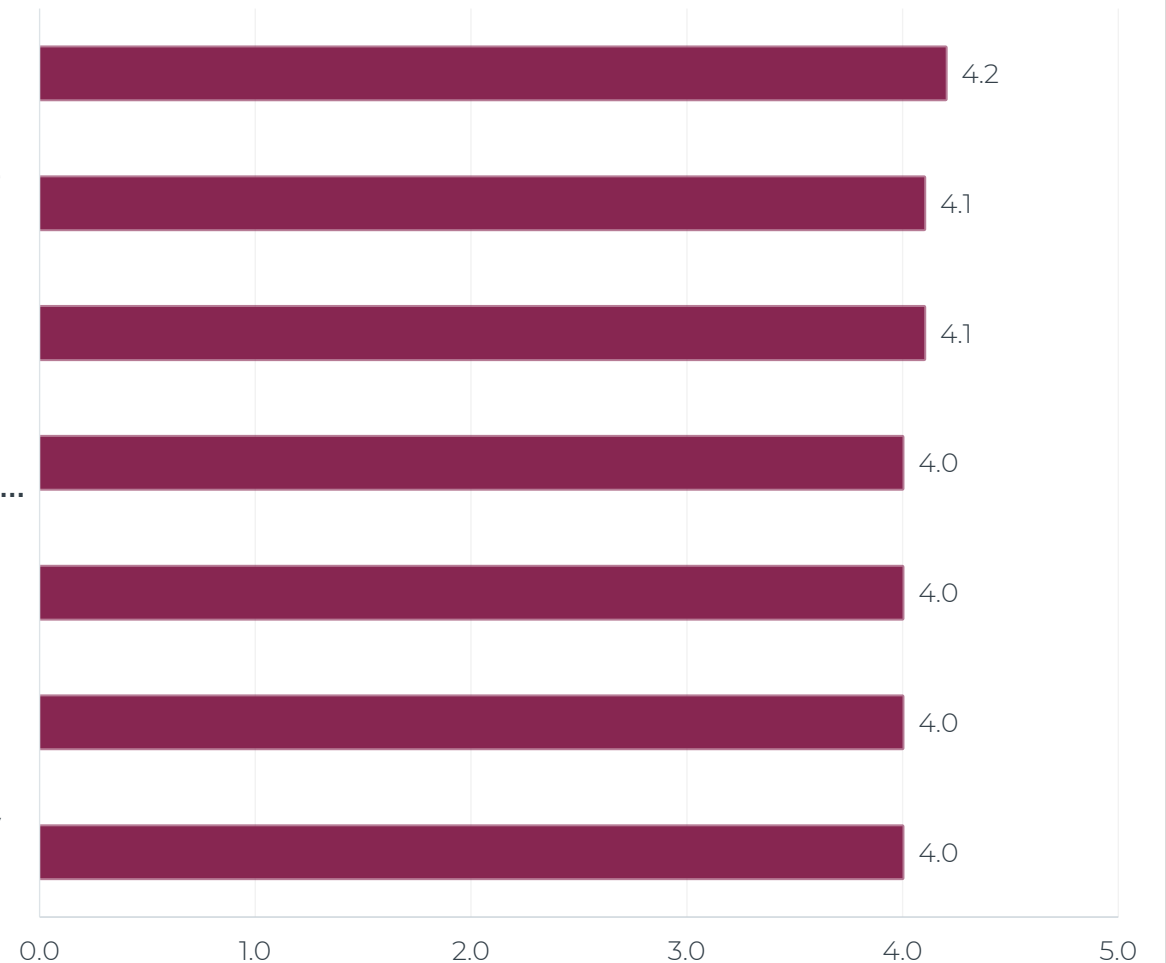
How important is the NBDF umbrella organization for the oversight of the NRB and its guiding principles?

How well will the proposed oversight and operational plans facilitate adherence to the proposed HEDI principles for equity and inclusion in...

How well do the proposed oversight and operational plans for the NRB embody the Guiding Principles?

How well do the proposed oversight and operational plans for the NRB reflect the Vision & Mission?

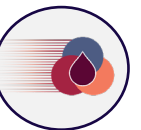
How effective will NRB be in facilitating collaboration among community organizations?



n = 85



Free Text Comments: 15 Themes



Open Ended Responses Themes

Too long and complex (n=24)

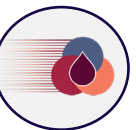
- “... create some brief, targeted and focused communication around LEEs...”
- “... Simplify the definition into a 5th grade level...”

Need for LEE education/mentorship in research (n=20)

- “Provide comprehensive training so LEEs recognize their expertise and feel empowered to participate...”
- “Allow LEEs the opportunity to be well versed in the concepts behind study proposals...”

Need specifics about implementation and accountability (n=14)

- Needs to include accountability, communication, and how researchers and LEEs will interact
- “... there is no "how..."



Open Ended Responses Themes

Great concepts/thank you (n=13)

- “Fantastic job... thank you for empowering those who should have a voice”
- “Thank you for including LEEs”

Terms require definition (n=12)

- “There may be some confusion stemming from “caregivers.”
- Adopt “Easier language....”

HEDI specifications are incomplete (add political, religious, economic diversity; need more about equity) (n=12)

- “Doesn't talk about health equity, doesn't talk about inclusion.”
- “It does not include anything regarding diversity of thought or political opinion...”

Open Ended Responses Themes

listen and work together with mutual respect (n=12)

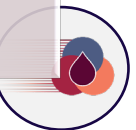
- "...it is a real challenge to bridge the gap and make a mutually-respected relationship between doctors/researchers and LEEs..."
- How about "each and every person will be seen as a unique individual and treated with the same respect and consideration we would want for ourselves."

Concerns about limitation of LEEs (n=10)

- "I understand why NBDF would want to include LEEs but they don't really have a place in guiding research..."
- "I'm just not sure that patients know what research is needed."

Involve other organizations/avoid redundancy/thoughtful selection of stakeholders and leadership (n=8)

- "Keep those in leadership positions across multiple organizations apprised of new developments."
- "...Some groups will overlap in activities and mission and thus will at times need cross-representation."



Open Ended Responses Themes

Wording is too vague (n=5)

- “Mission is a lot of “business speak” that is so vague that it is almost meaningless.”
- “This is vague. It's a bunch of words and ideas and I don't see the thread that pulls it all together. I don't understand.”

LEEs in leadership is important (n=5)

- “... I would have felt more inspired by language that more clearly put LEE within the leadership driving the research”
- “I think that if LEEs are intended to implement change, they should have some influence on funding.”

Involve LEEs in all stages of research (n=4)

- “Include in development of study and be a part of ongoing assessment of study”
- “It is difficult to include LEEs at every level and they might not be necessary on each level. That said LEEs should be included in a majority of the steps of research.”



Open Ended Responses Themes

Need roadmap on how this leads to better access and quality of care (n=3)

- Focus on “how this will improve our access to care and the quality of that care.”
- Isn't "thriving" more directly the result of access to expert team.... How does "having policies making research easier"

Funding for LEE participation (n=3)

- “... some sort of compensation will need to be considered...”
- “... are they going to be compensated? In my opinion they should all be volunteers to prevent bias.”

Need for personal application (n=2)

- “Show the practical benefit to me as a patient.”
- “... more opportunities to engage in a way that is meaningful to me.”

