Prioritizing research in bleeding disorders:

Here's what we heard from you

As we develop our National Research Blueprint, our focus is to identify and address the most pressing needs in bleeding disorders today.



Thank you to everyone who participated in a community-wide survey early in 2021 to share your views on what areas should be a priority for research.

Key highlights:

#1

The #1 ranked area for research focus: continuing the HTC model of care



#2

Across respondents, you've asked to see more research



on new therapies across all bleeding disorders

#3

Access to care, including differences in care in various communities, is a big priority

for you and one that is important for us too



Many also want to see more access to specialized care, such as health professionals who are prepared to address ultra-rare disorders.

You reported certain lifestyle considerations that should be prioritized for research, including:

Mental health





Treatment for aging populations





We had incredible participation for this survey from individuals, caregivers, physicians, allied health professionals and researchers to ensure our work mirrors your voices.

335



125



112 head care prof



