



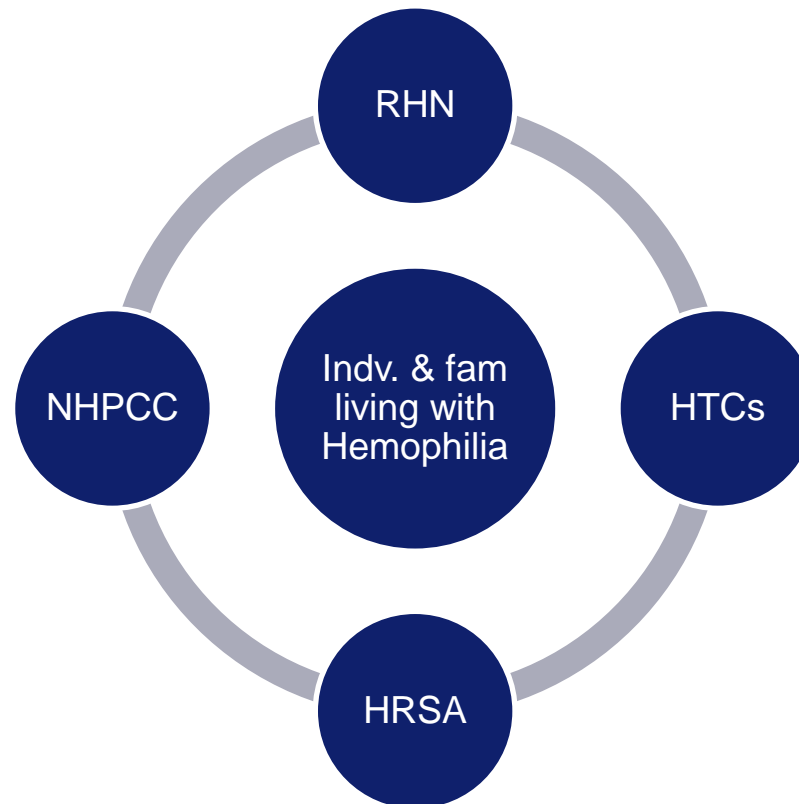
Hemophilia Program Kickoff Meeting

July 19, 2022

Melissa Creary, PhD, MPH
Senior Director, Office of Public Health Initiatives
ATHN

Background

Since its inception, ATHN has been the site of the National Hemophilia Program Coordinating Center (NHPCC) and has successfully secured the award to continue hosting the NHPCC through the 2022-2027 grant period.



Key Project Activities

1. Establish work groups comprised of regional and HTC representation
2. Maintain a secure data system
3. Collaborate with the RHNs & HTCs in tracking and reducing joint bleeds
4. Provide regional and HTC staff technical assistance
5. Increase evidence base & best practices for individuals with hemophilia
6. Develop and maintain a national online repository
7. Collect & disseminate resources on best practices through a public/password-protected online shared workspace.
8. Collaborate w RHN to support HTCs for a national QI project to identify best and promising practices improving transition across the lifespan.

Key Project Activities

1. Establish work groups comprised of regional and HTC representation
2. Maintain a secure data system
3. Collaborate with the RHNs & HTCs in tracking and reducing joint bleeds
4. Provide regional and HTC staff technical assistance
5. Increase evidence base & best practices for individuals with hemophilia
6. Develop and maintain a national online repository
7. Collect & disseminate resources on best practices through a public/password-protected online shared workspace.
8. Collaborate w RHN to support HTCs for a national QI project to identify best and promising practices improving transition across the lifespan.



Provide regional and HTC staff technical assistance

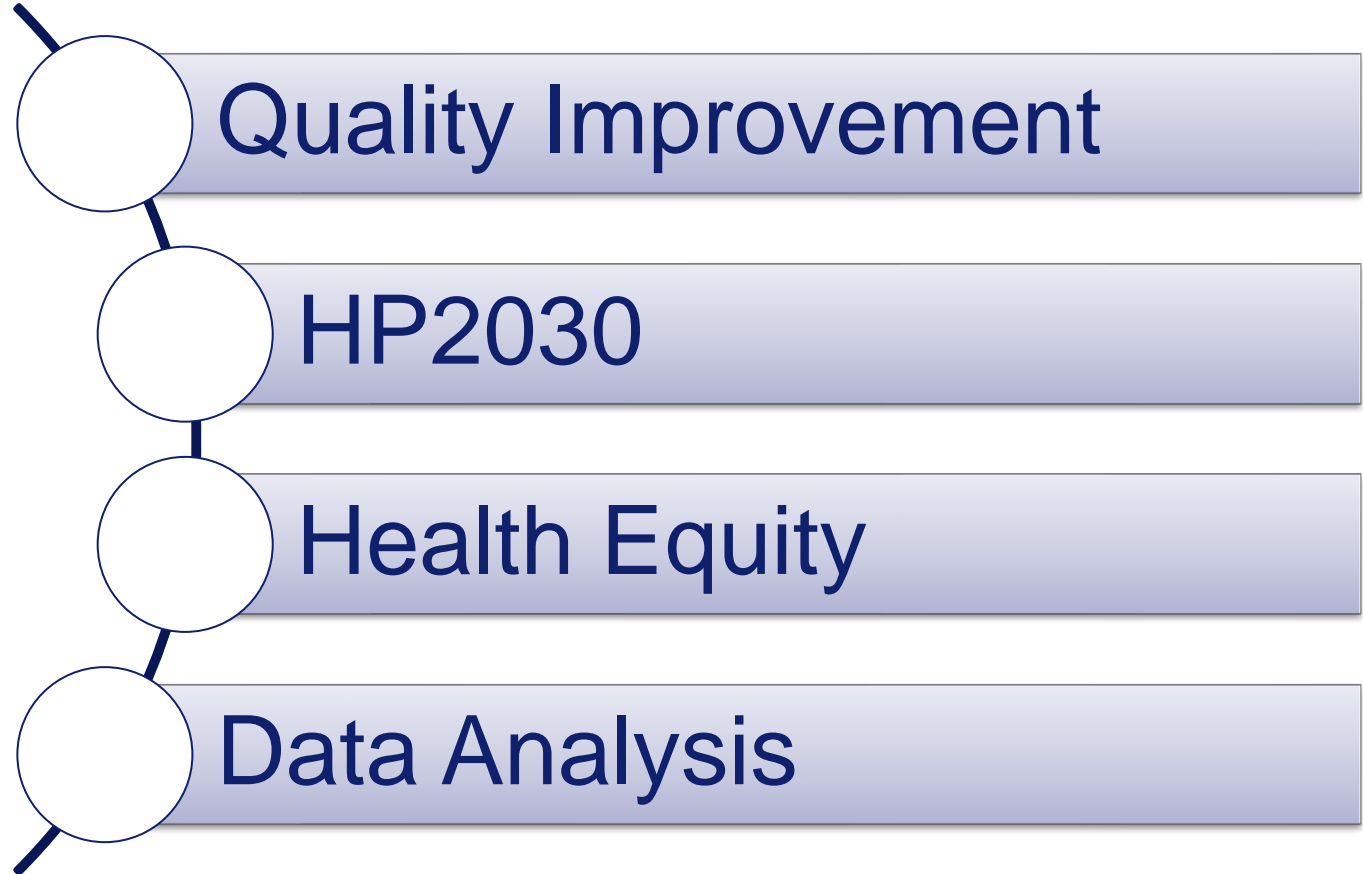
Webinars

In-person Meetings

- RHN Leadership
- Bi-annual Joint
- Ad-hoc

Trainings

Reference Hub

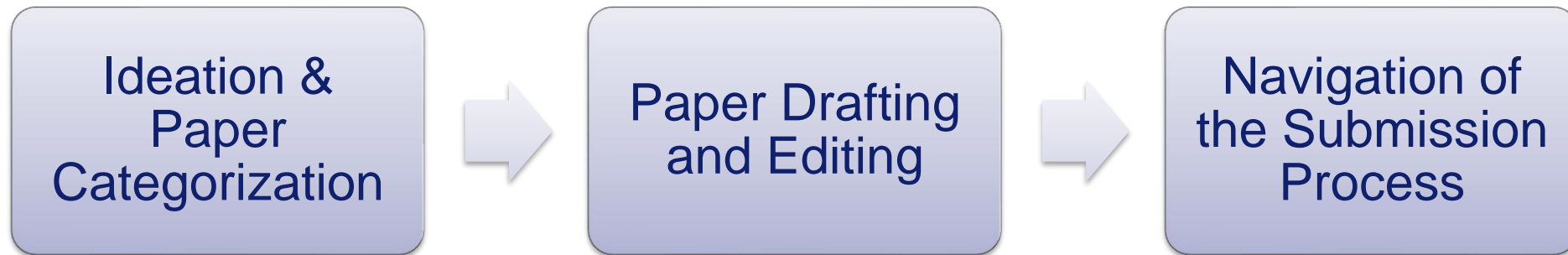




Increase evidence base & best practices

- Establish publication pipeline for RHN and HTC's
- Provide publication consulting to RHN and stakeholder organizations

3 PHASES





5-Year National QI project

- 2-year pilot project with a full rollout to all HTC's in grant years 3-5
- Focused on increasing the number of individuals 12 years and older seen in a comprehensive care clinic with a health care transition plan
- The NHPCC and RHNs will begin the national QI project with an HTC needs assessment to identify the groups where transition guidance is most needed by HTC's.



National QI Project | The NHPCC will...

- Develop measurements; means of data collection; data analysis, reporting, dissemination
- Provide infrastructure for the National QI Project Work Group
- Lead promotion of the project nationally through HTC-level communications
- Provide QI support as needed through the process, including QI CoP
- Provide QI trainings relevant to current national project
- Provide infrastructure for the project and for participants

The NHPCC will work with the RHNs to:

- Determine the selection process for work group participants
- Develop plan to identify target populations for transition
- Identify suitable pilot sites for year 1, and subsequent sites for years 3-5
- Develop a communication plan for sharing QI project process with HTC's
- Identify and share best and promising practices at HTC's

Program Expectations

- By the end of this 5-year cycle, the NHPCC will be a nationally recognized coordinating center utilized more by HTC staff, researchers, and the RHN.
- We are looking forward to supporting the national efforts towards increased intention around health equity and inclusion for the bleeding disorders community
- We are seeking and looking forward to increased collaborative energy towards the completion of shared goals between the RHN and the NHPCC

