



WFH Guidelines for NMO Capacity Development

Framework and Capacity
Assessment tool

July 2022

TABLE OF CONTENTS

Acknowledgements	2
Acronyms	2
A. Introduction	3
B. NMO CD Guidelines: Framework and Approach	4
C. NMO Capacity Assessment Tool: Description.....	7
D. NMO Capacity Assessment and Development Guide.....	9
Annex 1: NMO Capacity Assessment Tool	16
Component 1: Organizational Direction and Governance	17
Component 2: Programs and Advocacy.....	23
Component 3: Systems and Structure.....	29
Component 4: People and Community.....	34
Component 5: Funding and Finance	37
Component 6: Collaboration and External Relations	40
References.....	44

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ACRONYMS

CDAP	Capacity Development Action Plan
CEO	Chief Executive Officer
NMO	National Member Organization
NMO CD Guidelines	WFH Guidelines for NMO Capacity Development
NMO CAT	NMO Capacity Assessment Tool
PWBD	People with inherited bleeding disorders
RM	Regional Manager
SWOT	Strengths, Weaknesses, Opportunities and Threats
WFH	World Federation of Hemophilia

A. INTRODUCTION

The World Federation of Hemophilia (WFH) has been working in partnership with its national member organizations (NMOs) for nearly 60 years to improve and sustain care for people with inherited bleeding disorders (PWBDs) around the world.

The NMOs play a vital role in promoting access to treatment and improving care for people living with inherited bleeding disorders in collaboration with health care professionals (HCPs) and relevant government agencies. As such, the WFH has provided support over the years to help strengthen organizational capacities of NMOs through offering grants, training, and technical assistance. Aside from these, the WFH also believes that clear benchmarks and regular assessments will help guide NMOs in developing their capacities based on best practices in areas such as governance and leadership, volunteer management, program delivery, and stakeholder relations, leading to greater effectiveness.¹

In relation, from April 2021 to May 2022, the WFH developed the Guidelines for NMO Capacity Development (NMO CD Guidelines). A working group consisting of NMO representatives and relevant WFH staff was created to oversee the development process.

At various stages of the development of the NMO CD Guidelines, the WFH Board of Directors, Accreditation Committee, NMO representatives, relevant regional stakeholders, and staff were consulted. Pilot assessments were also conducted in Mexico and the Philippines. Comments and suggestions gathered throughout the development process informed the final draft. The NMO CD Guidelines were also presented at the Global NMO Training (GNMOT) held in May 2022.

The NMO CD Guidelines are based on a review of the WFH Hemophilia Patient Organization's Self-assessment Tool developed in 2011, as well as other related literature on best practices in organizational development and capacity assessment used by nonprofit organizations, including hemophilia organizations. Relevant WFH resources, such as Hemophilia Societies: Challenges and Development,² the WFH By-laws, and others, were also used as references.

The NMO CD Guidelines offer a systematic approach to organizational capacity assessment and development. They include a framework which describes the general concept of and approach to organizational capacity development, and a self-assessment tool (NMO Capacity Assessment Tool or NMO CAT) designed to help the organization understand, measure, and improve its performance.

Results of the assessment can be used in the creation of the NMO's capacity development plan which serves as a roadmap for organizational development. However, it is important to note that although the NMO CD Guidelines attempt to provide consistency in the approach to capacity assessment, the NMO capacity development plan is context specific. Capacity-building initiatives and priorities are based on the NMO's current capacity level and the context in which they are operating.

The NMO CD Guidelines (framework, approach, and assessment tool) are further described in the following sections. A copy of the NMO Capacity Assessment Tool (NMO CAT) can be found in the Annex section of this document along with a list of related literature and relevant resources.

1 WFH Strategic Framework and 2021-2025 Priorities, June 2021 <https://wfh.org/wp-content/uploads/2021/12/WFH-Strategic-Plan-2021-2025.pdf>

2 O'Mahony, B. (2000) 'Hemophilia Societies: Challenges and Development (Revised 2011)'. WFH Hemophilia Organization Development Series. Published by the 2000, revised 2011. Available at: <https://www1.wfh.org/publication/files/pdf-1239.pdf>. (Accessed: August 2021).

B. NMO CD GUIDELINES: FRAMEWORK AND APPROACH

“ORGANIZATIONAL CAPACITY is the ability of an organization to perform and sustain itself over time in line with its mission and objectives.”³

“ORGANIZATIONAL CAPACITY DEVELOPMENT is an intentional, collaborative effort to strengthen an organization’s processes, knowledge, relationships, assets, or behaviors to improve its performance.”⁴

Framework

Strong, effective NMOs are key to reaching more individuals living with bleeding disorders and improving their access to care and treatment.⁵ As such, the WFH NMO CD Guidelines were developed to support the ongoing organizational development of NMOs to better deliver services, and effectively implement advocacy and other programs, to improve access to care and treatment for PWBDs.

The NMO CD Guidelines aim to help NMOs identify organizational strengths that they could capitalize on, as well as determine capacity areas that need improvement to better design and implement their systems, programs, and services. Results of the assessment are used to create the organization’s capacity development action plan.

In assessing and developing the organization’s capacities, the NMO CD Guidelines framework (Figure 1) proposes to investigate six (6) key organizational components and relevant capacity areas associated with each (Figure 2). The principles of equity, diversity, and inclusion are integrated into each component. These components are interrelated and collectively characterize a strong and effective organization.

As these organizational components and capacity areas are strengthened, the NMO’s ability to achieve a well-managed and responsibly governed organization also increases (as depicted by the triangle in Figure 1).



Figure 1: NMO Capacity Development Framework

3 USAID Learning Lab (2021) ‘Monitoring Organizational Capacity Development Efforts, Version 2’. Program Cycle, Monitoring Toolkit. Available at: https://usaidlearninglab.org/sites/default/files/resource/files/monitoring_org_cap_dev_efforts_final2021.pdf (Accessed: May 2022)

4 ibid

5 WFH Strategic Framework and 2021-2025 Priorities, June 2021 <https://wfh.org/wp-content/uploads/2021/12/WFH-Strategic-Plan-2021-2025.pdf>



Figure 2: Capacity Areas

The six organizational components are described as follows:

1. **Organizational Direction and Governance:** Elements that collectively articulate the organization's common purpose and direction. They include a clear expression of the organization's reason for existence (mission) and what it aspires to become or achieve (vision), which are consistently used to direct actions and set priorities (goals and strategy) for the organization.
2. **Programs and Advocacy:** Programs and activities of an organization that accomplish its vision and mission.
 - a) **Programs** refer to a set of related measures or activities with a particular long-term aim.
 - b) **Program Development** refers to the cyclical process of planning, managing, monitoring, and evaluating programs.
 - c) **Advocacy** refers to a process of influencing key individuals, organizations, and decision makers to maintain or change policies, practices, and standards of care (the latter is in the context of bleeding disorders community).
3. **Systems and Structure:** Set of processes and procedures, as well as physical and technical assets used by an organization, to ensure that its objectives and various aspects of the organization's operations can be fulfilled.
4. **People and Community:** Capacities of management team/staff, members, and volunteers of the organization, as well as the organization's capacity for community engagement and chapter development (if applicable).
5. **Funding and Finance:** Planning, organizing, controlling, monitoring, and growing financial resources necessary to achieve organizational goals and objectives. Includes fund development strategies and financial resource management policies.
6. **Collaboration and External Relations:** Engagement, communication, and coordination with the WFH and relations with other organizations and stakeholders.

Capacity Development Approach

Figure 3 shows the general approach in the capacity assessment and development process.

This process is used as a guide in outlining the different steps involved in the capacity assessment process as well as the development and implementation of the organization's capacity development action plan. Details of which are described in Section D (NMO Capacity Assessment and Development Guide).

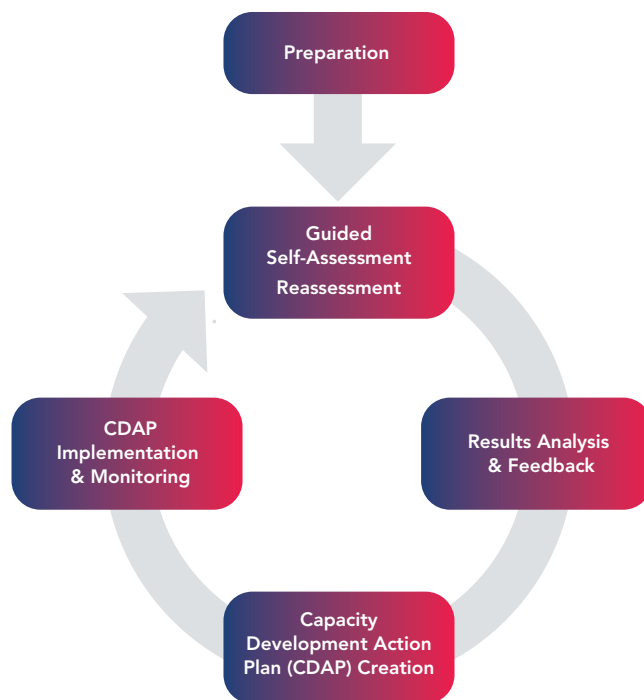


Figure 3: Capacity Development Process

In general, any capacity development effort starts with a preparatory phase prior to the facilitated and interactive self-assessment process. In this phase, it is important to review relevant materials, orient key actors of the process, identify the participants for the assessment, and agree on the meeting mode to be used.

The facilitated self-assessment process uses the NMO CAT as a guide. The NMO CAT is organized as a four-point grid that describes different organizational capacity levels based on benchmarks. The NMO CAT is described in more detail in Section C of this document and a copy can be found in Annex 1.

The result of the assessment is then analyzed and shared with the NMO to inform the creation of their capacity development action plan (CDAP). This plan identifies the NMO's strategic priorities and provides them with a roadmap for organization development that is implemented within a 3-year period.

During the implementation of the CDAP, it is recommended to conduct a mid-term review to determine whether any changes need to be made to the existing action plan. At the end of three years, an evaluation or reassessment is conducted.

C. NMO CAPACITY ASSESSMENT TOOL: DESCRIPTION

The NMO Capacity Assessment Tool (NMO CAT) is designed to measure the general capacity of an organization based on the six key organizational components described in the framework. It is a self-assessment tool that helps the NMO to identify capacity areas that need strengthening or further development.

As a self-assessment tool, it provides insights (and evidence) from and for people within the NMO. It brings together people from different parts of the NMO to reflect on its processes and functions, and scores itself based on benchmarks or points of reference.

Results and information gathered in the process can be used to determine concrete actions, based on agreed priorities, that may help address identified problems and gaps. In addition, as this allows the NMOs to define their own solutions based on their context, ownership and accountability of their plan also increase. This contributes to the sustainability of the interventions in the long run.

However, it is important to note that this assessment is focused on internal reflection and does not necessarily gather external opinions. In cases where external inputs are deemed necessary, a separate or complementary survey, tool, or process can be used to enhance and/or further validate data gathered from NMO CAT. Relevant documents collected prior to the assessment can also be used in the results analysis.

Tool Structure

The NMO CAT is divided into **six components** as highlighted in the framework (Figure 1):

- 1 Organizational Direction and Governance
- 2 Programs and Advocacy
- 3 Systems and Structure
- 4 People and Community
- 5 Funding and Finance
- 6 Collaboration and External Relations

Listed under each component are several capacity areas (Figure 2) which are used as a guide for the assessment. A total of **40 capacity areas** are integrated in the tool. For each capacity area, there are four statements depicting situations that describe the different capacity levels of an organization in a continuum (from Level 1: Low to Basic Capacity to Level 4: Outstanding Capacity).

The tool's grid structure was adapted from the McKinsey Capacity Assessment Grid (2001).⁶ However, the descriptions used per capacity area are mainly based on inputs from the working group, and review of other capacity assessment tools used by similar organizations, including the National Hemophilia Foundation. It is also informed by the WFH's core values, ethical principles, and by-laws.

⁶ Venture Philanthropy Partners (2001) 'Effective Capacity Building in Nonprofit Organizations'. Available at: <https://www.midot.org.il/Sites/midot/content/File/McKinsey%20Grid.pdf> (Accessed: July 2021)

Other Uses of the Tool

The NMO CAT can also be used to develop baselines, and for periodic capacity assessments that can help NMOs to measure how their capacity changes over time. Assessment results can also guide the NMO in developing proposals for program support from the WFH, wherever it may be applicable, and from other organizations.

For example, within the WFH, it may be used for the following:

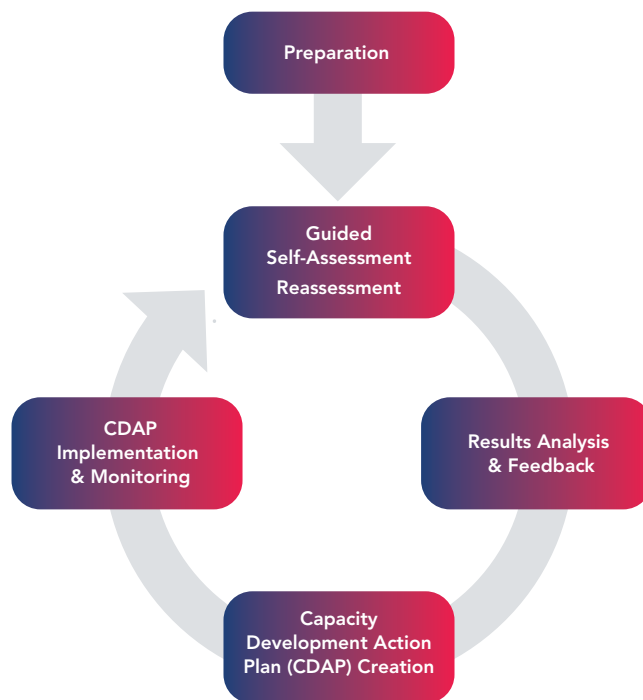
- During pre-assessment while initiating a Hemophilia Organization Twinning
- Applying for a change from Associate NMO to full NMO status
- After a major change in the NMO structure or leadership
- Before starting a major project

Section D describes how to use the tool and other preparations necessary prior to the assessment process.





D. NMO CAPACITY ASSESSMENT AND DEVELOPMENT GUIDE

Using the Capacity Development Process as a guide, this section outlines the different steps involved for each phase in the process.



This section also integrates tips and other resources relevant to the step being described.

IMPORTANT TIPS are indicated with this symbol: 

RELATED RESOURCES are identified with this symbol: 

1. PREPARATION: BEFORE THE ASSESSMENT

A. Orientation

The WFH Regional Manager (RM) holds an orientation meeting for the NMO Board (and Chapter Heads, if any) on the NMO CD Guidelines, including an overview of the tool and assessment process, and selection of participants. This is done either in person or virtually, ideally one month (or at least two weeks) before the scheduled assessment workshop.

Available relevant resources that the organization has or uses could also be requested during the orientation as part of the review prior to the assessment. For example, if there were situational analysis (e.g. SWOT analysis) that were conducted previously, this will be a good source of information that can be used to complement the results.

B. Selection of participants

The NMO is encouraged to seek broad participation and diverse representation of members, volunteers, the Board, and staff (if any) of their organization. The team who will participate in the assessment should be agreed on during the orientation.

The ideal group size for the assessment is around 8–10 participants, although it is possible for the assessment to be conducted with larger groups. However, the assessment will proceed more slowly with a larger group. It is recommended that the team that participates in the capacity assessment includes the following:

- At least one Board member (may include a Medical Advisor, if any)
- Board President or the Chief Executive Officer (CEO)/Executive Director (if any)
- At least one member representing the chapters (if any)
- At least one representative from each existing group (e.g. youth group, women's group)
- If the NMO has staff, it is recommended to include at least one representative from the human resources, finance, program implementation, and other relevant departments. In cases where the staff composition is small, it may be preferable to involve everyone.
- If the NMO does not have staff but has volunteers or members who help in running the organization, it is recommended to choose at least one volunteer who oversees finance, volunteer management, and program development and coordination.

Selected individuals should be explicitly informed beforehand that they need to participate in the assessment process from beginning to end. The assessment workshop might take around one to two days (approximately 10 to 12 hours in total) for in-person meetings, or longer if done virtually. In addition, the feedback and action planning sessions could also take one to two days. However, the entire assessment process including the planning session does not have to be conducted over consecutive days. The schedule depends on the agreement of the group.

Selected participants are sent a copy of the tool at least one week prior to the assessment workshop. Participants are encouraged to contact their respective RM should there be any questions or clarifications on the tool and/or the process.

C. Selection of the meeting mode (in-person or virtual)

An in-person workshop is preferable where all the respondents mentioned above can share ideas and discuss the assessment of their organization. Alternatively, if an in-person meeting is not feasible, the assessment could also be conducted virtually, or as a combination of both.

Preparations to be considered depending on the selected meeting mode are as follows:

- **In-person assessment:** This encourages better communication between the participants and allows for longer periods of focused work. When meeting physically, the RM and/or facilitator should seek to:
 - ✓ Have a comfortable place to meet, that can allow for an extended meeting if needed
 - ✓ Provide each participant with a physical copy of the tool (in case they did not bring their copy) along with writing material
 - ✓ Have a computer, internet connection, and a projector (or a white board), and
 - ✓ Allocate time to take notes and review the assessment results
- **Virtual meeting:** When this option is selected, the RM and/or facilitator should be mindful of the challenges associated with it such as tiredness, lack of focus, and others. Outlined below are some recommendations to overcome these difficulties:
 - ✓ Allocate shorter meeting blocks (maximum two hours per session)
 - ✓ Choose a communication platform that is most accessible to the participants, but always with the capabilities to have video stream. It is strongly recommended that each person have their camera turned on to facilitate discussion.
- **Combination:** The assessment could also be done using both modes. If using this option, it is recommended that the initial meeting be done in-person and succeeding sessions conducted virtually.

2. GUIDED SELF-ASSESSMENT: HOW TO USE THE TOOL

A. Complete the NMO CAT (Individually)

Prior to the assessment workshop, the RM sets up an orientation meeting to give an overview of the process.

Participants are then asked to assess their organization by completing the tool provided (NMO CAT). Participants are encouraged to include comments as applicable.

The tool takes about 10–15 minutes to complete. Completed assessments can be emailed to the respective RM, and a copy of the completed form needs to be brought to the assessment workshop.



In completing the tool, it is important to keep the following in mind:

- Not all the questions may apply to all NMOs. If there is an aspect that you think does not apply to your organization or you think should be changed or included in the questionnaire, please indicate N/A in addition to any other comments in the 'Comments' section.
- Be honest in your replies. The purpose of the tool is not to judge but to support organizational growth.
- There are no right or wrong answers. Two individuals may answer the same question differently. Answers will be discussed as a group after each respondent has completed the assessment tool.⁷

B. Discussion and consensus building

Participants come together on a date and at a place previously agreed upon to discuss and reach consensus on the capacity scores for their organization. Ideally, this process is facilitated by a team of at least two people (or preferably three, one of which is a note taker). It usually takes about one to two days (or around 10 to 12 hours) to complete this process, depending on the meeting mode identified or agreed upon.

- **Agreed Criteria:** Before the assessment begins, it is advisable that the group discusses and agrees on the criteria for scoring and decision-making.

For example, the two-thirds rule can be applied, i.e. if the organization meets two thirds of the criteria, then it can be considered to be at that capacity level.⁸ There are also some criteria that may be critical to be achieved before advancing to the next level (footnoted as WFH by-laws or accreditation criteria). In this case, an organization can only advance to the next stage when it has met those criteria referenced within the tool.

⁷ World Federation of Hemophilia (2011) 'Hemophilia Patient Organization Self-Assessment'. Available at: <https://www1.wfh.org/publications/files/pdf-1605.pdf>. (Accessed: July 2021).

⁸ Management Sciences for Health (2013) 'BLC Organizational Capacity Assessment Tool User Guide'. Building Local Capacity for Delivery of HIV Services in Southern Africa. Available at: https://msh.org/wp-content/uploads/2015/09/2015_08_msh_organizational_capacity_assessment_tool_ocat.pdf (Accessed: April 2022)



It is important to **allow everyone to voice their opinion**. However, participants who are not willing to openly express their views should also be respected. In instances where some participants may not feel qualified to rate the organization on certain subcomponents (for example, Financial Management), it is better to give them a chance to “pass” rather than rate the organization based on copying other participants’ scores or guessing.⁹

Process:

- ✓ The **facilitator first explains the scale scores**, introduces the first component and associated subcomponents/capacity areas, and reads the description of the first subcomponent before asking the participants to “rate” their organization.
- ✓ Each **participant is then asked to share and discuss with the group** their rating of the capacity area, and the rationale and/or relevant comments about it (using the completed tool as a guide). It is advised that the President/CEO goes last so as not to influence the others’ responses. The facilitator notes each score on the board (or projected on the screen, if available) for everyone to see.
- ✓ After each participant shares their rating, **the group is asked to discuss and come up with a consensus of the rating** per capacity area.
- ✓ If participants wish to change their scores after having heard from the rest of the group, the facilitator/s and note taker should take note of these in the comments section of the tool.
- ✓ After group members have given their scores, the note taker enters the information into a scoring sheet. At the end of scoring per capacity area, the group is also asked for **examples of supporting documents or other means of verification**. The means of verification are usually used during the future evaluation or re-assessment as reference for review.
- ✓ At the end of the discussion for each Organizational Component, participants are asked if they can think of **any improvements or changes** that could be made to the way the organization works overall. These should be noted under the relevant comments’ column.



It is important to keep in mind that each organization has unique strengths and weaknesses. It may not be possible to find a “**perfect match**” using the scale score descriptions. In such cases, the facilitators and participants should **look for the description which most closely matches that of the organization**.¹⁰



WFH resources like the following can be used for consensus-building processes and can be downloaded from the WFH e-Learning platform, or a copy may be requested from the WFH:

- ‘*Group Dynamics and Team Building*’ by Ann-Marie Nazzaro, Joyce Strazzabosco¹¹

⁹ Ibid

¹⁰ Management Sciences for Health (2013) ‘BLC Organizational Capacity Assessment Tool User Guide’. Building Local Capacity for Delivery of HIV Services in Southern Africa. Available at: https://msh.org/wp-content/uploads/2015/09/2015_08_msh_organizational_capacity_assessment_tool_ocat.pdf (Accessed: April 2022).

¹¹ Nazzaro, A. and Strazzabosco, J. (2009) ‘Group Dynamics and Team Building’. WFH Hemophilia Organization Development Series. Available at: <https://www1.wfh.org/publication/files/pdf-1245.pdf> (Accessed: June 2022).

3. RESULTS ANALYSIS AND FEEDBACK

A. RESULTS ANALYSIS

- The scores entered in the scoring sheet are checked by the facilitators/RM and relevant documents are reviewed. A summary is then prepared with scores for each organizational component and capacity areas related to it, together with a summary of comments and suggestions that were noted.
- Other relevant information that was gathered, if any, can also be used to supplement or support the results analysis. This information can also be integrated in the summary of the results.

B. FEEDBACK

- The summary of the results and analysis are presented to the participants. Results, along with comments and suggestions, are then discussed for clarification and noted.
- The information presented is also shared with the Board and key people involved in the planning process to help determine which capacity areas require improvement. In case the organization deems it necessary to seek external inputs, this should be noted and agreed upon by the group and leadership.

4. ACTION PLANNING

Action planning is an important part of the capacity development process as it provides the organization with a roadmap for development. The capacity development activities are more likely to lead to sustainable change if the NMO has strong ownership of its action plan.

This process could take one day or longer, depending on the agreement and pace of the group. The following are important points to consider for action planning:

- Findings that were presented are reviewed and discussed to identify appropriate steps to be taken to improve areas of weakness and build on areas of strength. Comments and suggestions shared can also help in deciding the priority areas for capacity building.
- The person or team who will be responsible for monitoring the action plan should also be identified after activities and priorities have been agreed upon.
- A summary of proposed actions and timeline is drafted by the organization to be shared with a wider group for consultation and validation.



The following are WFH resources that can be used for action planning. These can be downloaded from the WFH e-Learning platform, or a copy could be requested from the WFH.

- '*Action Planning*' by Gordon Clarke¹²
- '*Planning and initiating projects: A guide for emergent NMOs*'¹³

12 Clarke, G (2010) 'Action Planning'. WFH Hemophilia Organization Development Series. Available at: <https://www1.wfh.org/publication/files/pdf-1241.pdf> (Accessed: June 2022).

13 World Federation of Hemophilia (2015) 'Planning and initiating projects: A guide for emergent NMOs'. Available at: <https://elearning.wfh.org/resource/planning-and-initiating-projects-a-guide-for-emergent-nmos/> (Accessed: June 2022).

5. CAPACITY DEVELOPMENT ACTION PLAN: IMPLEMENTATION AND MONITORING

Monitoring and evaluation are integral parts to a successful capacity-building initiative. This process provides data and evidence that could be used in determining the effectiveness of the interventions.

The assigned implementation and monitoring team tracks the progress of the capacity development activities. A midterm review is also recommended to determine whether any changes need to be made or added to the existing action plan, as well as lessons learned, or new knowledge acquired in the process.

6. EVALUATION AND REASSESSMENT

At the end of the three years, an evaluation is normally conducted to assess outcomes and needs for further development. On the other hand, reassessment using the NMO CAT can also be conducted after the three-year period of implementation to determine whether there were changes or improvements to the capacity areas. The initial assessment could be used as a baseline and succeeding assessments can be used to track changes or improvements over time.

ANNEX 1: NMO CAPACITY ASSESSMENT TOOL

General Information:

Name (optional): _____

NMO: _____ Country: _____

Instructions:

This Assessment Tool is divided into **six key organizational components** as shown below and **each component includes several capacity areas** (total of 40 capacity areas).

- | | |
|--|--|
| 1 Organizational Direction and Governance
..... | 4 People and Community
..... |
| 2 Programs and Advocacy
..... | 5 Funding and Finance
..... |
| 3 Systems and Structure | 6 Collaboration and External Relations |

STEP 1: Complete the assessment tool individually

- For each capacity area, please check the box that best describes the current situation of your organization. If none of the descriptions are applicable to your organization, place N/A under the comments section. Use the comments section if you have any comments or suggestions. After completion, kindly email it to your respective Regional Manager and bring a copy of the completed tool to the assessment workshop. Your honesty is essential and appreciated.

STEP 2: Discuss rating as a group

- During the assessment workshop, each participant is asked to share and discuss their rating with the group. After everyone has shared, the group discusses and agrees on the rating for each of the capacity areas. Relevant comments are noted in the comments section of the tool.
- If the participants wish to change their scores after hearing from the rest of the group, the facilitators and note taker should add these revisions in the comments section of the tool.
- At the end of the discussion for each component, participants are also asked for any improvements or changes that could be made to the way the organization works overall. Suggestions are noted in the comments section.

COMPONENT 1: ORGANIZATIONAL DIRECTION AND GOVERNANCE

Comments

Description: Elements that set the organization’s direction, such as vision, mission, goals, and strategies (VMGS), as well as leadership and governance.

Instruction: For each capacity area, please check the box that best describes your organization’s status or performance. If none of the descriptions are applicable to your organization, place N/A under the comments section, along with other comments/suggestions, if any.

Capacity Levels

Capacity Areas	1 Low to basic	2 Moderate	3 Advanced	4 Outstanding
DIRECTION				
1.01 Vision, Mission, Goals, and Strategy (VMGS) Expression of the organization’s reason for existence (mission), and what it aspires to become or achieve (vision) which are used to direct actions and set priorities (goals and strategy)	<input type="checkbox"/> Our organization does not have a written vision or mission statements, but has an action plan.	<input type="checkbox"/> Our organization has written vision and mission statements which are not in conflict with the WFH vision and mission. ¹⁴ These are not translated into a long-term strategic plan but are sometimes used to direct actions or set priorities for the organization. The Board is familiar with these statements, but these are not widely known across the organization.	<input type="checkbox"/> Our organization has clearly written vision, mission, and goals (VMG) which describe what it aspires to become or achieve. These are also in line with the WFH vision and mission. Our VMG are widely known among our Board, staff (if any), and its members, and are often used to direct actions and priorities. These are also translated into a strategic plan with clear objectives. However, these are not reviewed regularly to ensure that they reflect and address the current context of the organization and country.	<input type="checkbox"/> Our VMG clearly state and explain why our organization exists and what our organization aspires to become or achieve. These are aligned with the WFH vision and mission and are universally understood by the Board, its members, volunteers, and staff (if any). These are translated into a long-term strategic plan with measurable objectives and targets, well-defined timeframes, and measures of success. These are consistently used to direct actions and set priorities of the organization. These are also regularly reviewed to ensure that evolving (or changing) organizational and country contexts are reflected and addressed.

¹⁴ World Federation of Hemophilia By-laws (last approved by the WFH General Assembly on May 7, 2022), Appendix 1 <https://wfh.org/wp-content/uploads/2022/08/WFH-ByLaws-May2022.pdf>

Capacity Areas	Capacity Levels				Comments
	1 Low to basic	2 Moderate	3 Advanced	4 Outstanding	
DIRECTION					
<p>1.02 Organizational Values and Principles</p> <p>A common set of core values and principles which represents the best interests of people with hemophilia and other inherited bleeding disorders in the country.¹⁵</p> <p>The Principles of Equity, Diversity, and Inclusion (EDI) ensure fair treatment and opportunity for all and aim to eradicate prejudice.¹⁶</p>	<input type="checkbox"/> <p>Our Board members share a similar set of beliefs and values. However, this is not documented and shared within the organization.</p>	<input type="checkbox"/> <p>Our organization has a set of core beliefs and values which is well documented and outlines some guiding principles of equity, diversity, and inclusion. However, this is not widely known within the organization, and only used occasionally to inform organizational actions and decisions.</p>	<input type="checkbox"/> <p>Our organization has a set of core beliefs and values which is clearly written and includes guiding principles of equity, diversity, and inclusion. This is well known to many members and often used by the Board and management team to inform organizational actions and decisions.</p>	<input type="checkbox"/> <p>Our organization has a set of core beliefs and values which is clearly written and widely understood by most of the members and staff (if any). It also clearly outlines guiding principles for ensuring equity, diversity, and inclusion in the organization, as well as in its programs and activities. There is an organization-wide commitment to these principles that are consistently used to guide or direct actions and decisions of the organization.</p>	

15 World Federation of Hemophilia By-laws (last approved by the WFH General Assembly on May 7, 2022), Appendix 1.

<https://wfh.org/wp-content/uploads/2022/08/WFH-ByLaws-May2022.pdf>

16 The University of Edinburgh, accessed 17 June 2022 <https://www.ph.ed.ac.uk/equality-diversity-and-inclusion/about-edi/what-does-equality-diversity-and-inclusion-mean>

Capacity Areas	Capacity Levels				Comments
	1 Low to basic	2 Moderate	3 Advanced	4 Outstanding	
GOVERNANCE AND LEADERSHIP					
<p>1.03 Board Selection and Representation</p> <p>Process of selection to fill the vacancies on the Board, based on the organization's bylaws. Follows a clear nomination process and ensures representation is equitable, diverse, and inclusive.</p>	<input type="checkbox"/> <p>Our organization does not have a nomination and selection process but is working towards developing one.</p> <p>Board membership is drawn from a narrow spectrum of constituencies and has limited representation of people from diverse backgrounds, groups, and relevant expertise.</p>	<input type="checkbox"/> <p>Our organization has a nomination and selection process for Board members. However, term limits and Terms of Reference (ToR) are not clearly defined.</p> <p>Board membership is representative of the main groups within the bleeding disorders community and has some diversity in fields of practice and expertise.</p>	<input type="checkbox"/> <p>Our organization has a clear nomination and selection process for Board members which encourages the participation of diverse groups within the bleeding disorders (BD) community, especially the underrepresented sectors.</p> <p>General elections are held regularly.</p> <p>Term limits are well defined, and ToRs clearly outline the key functions and responsibilities of the Board.</p> <p>Board membership is representative of people from diverse backgrounds and groups within the bleeding disorders community, and with relevant expertise.</p>	<input type="checkbox"/> <p>Our NMO's Board nomination and selection process is well crafted with clear rules and actions to ensure the representation of different groups within the BD community, especially the underrepresented sectors.</p> <p>General elections are held regularly.</p> <p>Term limits are clearly defined, and ToRs detail the duties and responsibilities of the Board.</p> <p>Board membership is drawn from the full spectrum of constituencies relevant to the organization. It is representative of people from a broad variety of backgrounds and relevant expertise.</p>	

Capacity Areas	Capacity Levels				Comments
	1 Low to basic	2 Moderate	3 Advanced	4 Outstanding	
GOVERNANCE AND LEADERSHIP					
<p>1.04 Board Decision-making Process</p> <p>Decision making is the process of making choices by identifying a decision, gathering information, and assessing alternative solutions.</p> <p>This is guided by the organization's bylaws and informed by different stakeholder groups.</p>	<input type="checkbox"/> <p>Decisions regarding organizational direction are determined solely by either one individual or a small group.</p> <p>There is no clear process that facilitates input from relevant staff (if any) and stakeholders.</p>	<input type="checkbox"/> <p>Decisions on organizational direction are determined through a clear process with the participation of Board members.</p> <p>Some relevant staff (if any) are also consulted for input on major decisions regarding the organization and its strategic direction.</p>	<input type="checkbox"/> <p>Decisions on organizational direction are determined through a clear process and guided by the organization's bylaws. The process involves participation of the Board members, including representatives of the Medical Advisory Board (if any).</p> <p>Relevant staff (if any), stakeholders, and groups are also consulted on major decisions concerning the organization and its strategic direction.</p>	<input type="checkbox"/> <p>Decisions on organizational direction are determined and communicated through a clear, inclusive, and participatory process, and guided by the organization's bylaws.</p> <p>Board members, including the Medical Advisory Board and all relevant staff members (if any), are actively involved in this process.</p> <p>Board decisions also consider information gathered from consultations with members, as well as different stakeholders and groups.</p>	

Capacity Areas	Capacity Levels				Comments
	1 Low to basic	2 Moderate	3 Advanced	4 Outstanding	
GOVERNANCE AND LEADERSHIP					
1.05 Board Involvement and Accountabilities The Board provides strong direction and support, promotes the organization’s vision, mission, and clearly articulates the path to achieving the vision. It understands and fulfills its responsibilities and accountability.	<input type="checkbox"/> Board members are quite familiar with their roles and responsibilities but provide little direction and support to the leadership team. Board meetings are infrequent and/or have poor attendance.	<input type="checkbox"/> Decisions on organizational direction are determined through a clear process with the participation of Board members. Some relevant staff (if any) are also consulted for input on major decisions regarding the organization and its strategic direction.	<input type="checkbox"/> Board members have a good understanding of their roles, responsibilities, and accountability. They provide direction and set priorities for the organization whenever necessary. However, these are not always clearly articulated. They hold meetings occasionally with defined agenda. Attendance is generally good.	<input type="checkbox"/> Board members have an exceptionally good understanding of their roles, responsibilities, and accountability. They actively support and regularly promote the organization’s vision, mission, and strategies. The path towards achieving the organization’s vision is also clearly articulated. They set clear and concrete objectives that are aligned with the organization’s strategic plan and priorities to be accomplished every year. They hold regular meetings with defined agendas and outcomes, as well as regular and focused subcommittee meetings. Attendance in board and subcommittee meetings are consistently good.	

Capacity Areas	Capacity Levels				Comments
	1 Low to basic	2 Moderate	3 Advanced	4 Outstanding	
GOVERNANCE AND LEADERSHIP					
1.06 Succession Planning Ability to continue operations and management of programs in the event of an absence of or change in leadership.	<input type="checkbox"/> Our organization does not have a process (formal or informal) in place to cultivate the next generation of leaders.	<input type="checkbox"/> Our organization has a succession plan which identifies the key roles that need to be filled in the future. However, it does not have a clear process and program for developing capacities that will prepare potential leaders for the identified roles.	<input type="checkbox"/> Our organization has a clear succession plan that determines the key roles that need to be filled in the future and dedicated processes and programs for the development of future leaders. The succession plan and professional development program are informed by a diverse group.	<input type="checkbox"/> Our organization has an established succession planning process and clear leadership development plan and programs focusing on future leaders. The succession plan and programs are informed and developed by representatives from various groups, including the underrepresented sectors of the community.	

COMPONENT 2: PROGRAMS AND ADVOCACY

Description: Programs and activities of an organization to accomplish its vision and mission.

Instruction: For each capacity area, please check the box that best describes your organization's status or performance. If none of the descriptions are applicable to your organization, place N/A under the comments section, along with other comments/suggestions, if any.

Capacity Levels

Capacity Areas	1 Low to basic	2 Moderate	3 Advanced	4 Outstanding
PROGRAM MANAGEMENT				
2.01 Program Development and Implementation	<input type="checkbox"/> Our organization has limited capacity to conduct a needs assessment for program planning and development. There is no strategy for involving the community in program planning and design. Programs and/or activities are created mainly in response to funding availability and criteria.	<input type="checkbox"/> Our organization has some capacity to develop programs based on identified needs and priorities. It orients the community on its programs, but it does not consistently involve the community in needs assessment, program planning, design, and implementation.	<input type="checkbox"/> Our organization has sufficient capacity to develop, modify, and implement programs according to member needs and program gaps. It orients the community on its programs, and engages them in needs assessment, program planning, design, and implementation.	<input type="checkbox"/> Our organization is fully equipped to develop, modify, and/or create and implement new and innovative programs to meet member needs and identify gaps efficiently and effectively. It actively engages the community in all the relevant stages of the program development and implementation, and consistently integrates inputs from the community to inform program development and improvement.

Comments

Capacity Areas	Capacity Levels				Comments
	1 Low to basic	2 Moderate	3 Advanced	4 Outstanding	
PROGRAM MANAGEMENT					
2.02 Monitoring, Evaluation, and Learning (MEL)	<input type="checkbox"/> Our organization has no MEL plan and process for monitoring and evaluating program activities.	<input type="checkbox"/> Our organization has a basic MEL plan with identified outcome indicators. It also has a process for collecting data and reporting progress based on targets, but it is not followed consistently. Program evaluations are done only if required.	<input type="checkbox"/> Our organization has a well-defined MEL plan and process. It has a process for regular data collection and reporting progress based on set targets which are mostly followed. Program evaluations are not conducted consistently.	<input type="checkbox"/> Our organization has a well-defined MEL plan, and strategy and process for quality data collection and reporting. Assessments, reviews, and evaluations are conducted regularly to inform program planning, development, and implementation.	
EDUCATION AND TRAINING ACTIVITIES					
2.03 Educational Activities	<input type="checkbox"/> Our organization has a limited capacity to inform and educate its members on bleeding disorders care and treatment. Meetings are occasionally used for sharing relevant information.	<input type="checkbox"/> Our organization has some capacity to inform and educate its members. It holds at least one workshop per year (virtual or face-to-face) for members to educate on hemophilia care and treatment. This is sometimes supported by healthcare professionals (HCPs). When relevant, some content is created using the WFH Treatment Guidelines and/or other educational resources.	<input type="checkbox"/> Our organization has adequate capacity to organize education and training activities on bleeding disorders care and treatment. It holds on average, two to three workshops per year (virtual or face-to-face) for our members and volunteers to share and discuss relevant information and advancements in care and treatment of hemophilia and other bleeding disorders. Many of the workshops are supported and/or participated in by HCPs and other experts. When relevant, content is created using the WFH Treatment Guidelines and/or other educational resources.	<input type="checkbox"/> Our organization is fully equipped to organize regular (at least quarterly) workshops and/or training sessions each year (virtual or face-to-face) on comprehensive care and treatment of hemophilia and other bleeding disorders for the Board, relevant staff (if any), its members, and volunteers. Educational activities are mostly supported by and organized in collaboration with HCPs and experts. When relevant, content is created using the WFH Treatment Guidelines and/or other educational resources.	

Capacity Areas	Capacity Levels				Comments
	1 Low to basic	2 Moderate	3 Advanced	4 Outstanding	
EDUCATION AND TRAINING ACTIVITIES					
2.04 Diagnosis and Management of Bleeding Disorders	<input type="checkbox"/> Our organization does not provide training on the diagnosis and management of hemophilia and other bleeding disorders for HCPs. However, we share information provided on the topic by the WFH or other organizations.	<input type="checkbox"/> Our organization organizes at least one workshop per year (virtual or face-to-face) on the diagnosis and management of hemophilia and other bleeding disorders for HCPs. These workshops are only conducted for the HTC(s) in the capital city of the country.	<input type="checkbox"/> Our organization, in coordination with (or with the support of) our Medical Advisors and/or WFH expert volunteers, holds about two to three trainings/workshops per year (virtual or face-to-face) for HCPs on diagnosis and management of bleeding disorders. These trainings are conducted in major cities and provinces in the country.	<input type="checkbox"/> Our NMO has regular (at least quarterly) educational programs for healthcare professionals on diagnosis and management of bleeding disorders. These are conducted for HTCs in all the regions of the country and have the endorsement of the government.	
2.05 Economics of Care	<input type="checkbox"/> Our organization does not conduct training/workshops on the economics of hemophilia or other bleeding disorders care.	<input type="checkbox"/> Our organization conducts training/workshops for the core group of Board members on basic principles of health economics in relation to hemophilia and other bleeding disorders care at least once a year.	<input type="checkbox"/> Our organization conducts training/workshops for all Board members and relevant staff/volunteers/members (if any) on basic principles of health economics in relation to hemophilia and other bleeding disorders care at least once a year.	<input type="checkbox"/> Our organization offers regular basic and advanced training/workshops on economics of hemophilia and other bleeding disorders care for its board members, relevant staff (if any), members and volunteers at least once or twice a year.	

Capacity Areas	Capacity Levels				Comments
	1 Low to basic	2 Moderate	3 Advanced	4 Outstanding	
OUTREACH AND ADVOCACY ACTIVITIES					
2.06 Outreach and Awareness Raising	<input type="checkbox"/> <p>Our organization has a few outreach activities which are held in the capital city and target people living with hemophilia.</p> <p>Our organization celebrates World Hemophilia Day (WHD) as an opportunity for raising awareness using social media.</p>	<input type="checkbox"/> <p>Our organization conducts outreach activities in the main cities of the country to raise awareness and identify people with hemophilia.</p> <p>Our organization celebrates WHD as an opportunity for raising awareness using social media and, sometimes, in-person events in the capital city.</p>	<input type="checkbox"/> <p>Our organization has well-planned outreach programs in the main cities and some remote areas in the country aimed at increasing general awareness on bleeding disorders and identifying more people living with hemophilia and other bleeding disorders.</p> <p>Our organization celebrates WHD as an opportunity for raising awareness throughout the country, either through social media or in-person events.</p>	<input type="checkbox"/> <p>Our organization has a well-planned and coordinated outreach and awareness-raising programs aimed at identifying more people with inherited bleeding disorders, covering most regions of the country regardless of their bleeding disorder and gender and directed towards increasing general awareness on bleeding disorders.</p> <p>Our organization celebrates WHD as an opportunity for raising awareness throughout the country using social media and in-person events.</p>	

Capacity Areas	Capacity Levels				Comments
	1 Low to basic	2 Moderate	3 Advanced	4 Outstanding	
OUTREACH AND ADVOCACY ACTIVITIES					
2.07 Government Advocacy	<input type="checkbox"/> <p>Our organization does not have a defined advocacy strategy and has limited engagement with relevant government institutions/officials.</p> <p>Meetings with hospital administrators/HTCs, healthcare authorities and/or other relevant government officials are held on an ad hoc basis.</p>	<input type="checkbox"/> <p>Our organization has advocacy activities, but it does not have a well-defined advocacy strategy for government engagement.</p> <p>Meetings are occasionally held with hospital administrators, healthcare authorities, and/or other relevant government officials.</p>	<input type="checkbox"/> <p>Our organization has an advocacy strategy for government engagement, which is mostly aligned with the strategic plan and priorities.</p> <p>Based on this, our organization maintains regular dialogue with hospital administrators and relevant government officials. However, our organization is not officially recognized as a government partner.</p>	<input type="checkbox"/> <p>Our organization has a clear advocacy strategy in engaging and influencing policy decisions on hemophilia and other inherited bleeding disorders care and treatment, which is aligned with the strategic plan and priorities and is supported by trained members and volunteers.</p> <p>Our organization has regular dialogue with government officials as a recognized partner in the decision-making process related to treatment and care. It is a formal member of all inter-agency coordinating bodies overseeing provision of care and treatment for people with hemophilia and/or inherited bleeding disorders (such as national hemophilia committees, procurement bodies and others, if such exist in the country).</p>	

Capacity Areas	Capacity Levels				Comments
	1 Low to basic	2 Moderate	3 Advanced	4 Outstanding	
OUTREACH AND ADVOCACY ACTIVITIES					
2.08 Data Collection and Evidence-based Advocacy	<input type="checkbox"/> <p>Our organization has limited capacity in collecting data on people with hemophilia and other bleeding disorders in the country.</p> <p>Our organization does not use relevant data to advocate with healthcare decision makers for improved care and treatment for people living with hemophilia and other bleeding disorders.</p>	<input type="checkbox"/> <p>Our organization has some capacity for data collection and maintains a basic national registry.</p> <p>Our organization sometimes uses the information available to advocate with healthcare decision makers, but with no consistency.</p>	<input type="checkbox"/> <p>Our organization has well-established data collection programs and regularly updates its national registry.</p> <p>Collected data is consistently used by our organization for advocacy.</p>	<input type="checkbox"/> <p>Our organization has a national registry, and regularly collects and analyzes patient data using online tools. It uses data gathered from current research and advancements in care and treatment of bleeding disorders to support advocacy efforts.</p> <p>Our organization also uses this information to inform program planning and development.</p>	
2.09 Educational Materials for Programs and Advocacy	<input type="checkbox"/> <p>Our organization has limited educational resources that are shared among members on an as-needed basis.</p> <p>Our organization does not have the capacity to produce or translate existing relevant materials into the local language(s).</p>	<input type="checkbox"/> <p>Our organization has some educational resources that can be shared among members.</p> <p>These materials are mostly from the WFH and/or other organizations.</p> <p>Some resources are translated into the local language(s).</p>	<input type="checkbox"/> <p>Our organization has many educational materials from the WFH and/or other organizations which are shared with most members.</p> <p>Relevant materials are translated into the local language(s).</p>	<input type="checkbox"/> <p>Our organization regularly distributes materials to educate patients in the local language(s). These materials are either originally developed by our organization, and/or HCPs, or are resources produced by the WFH or other organizations.</p> <p>Educational materials that are translated into the local language(s) are also placed in a resource depository that is easily accessible by community members.</p>	

COMPONENT 3: SYSTEMS AND STRUCTURE

Description: Set of processes and procedures used by an organization to ensure that it can fulfill the tasks required to achieve its objectives and various aspects of the organization’s operations.

Instruction: For each capacity area, please check the box that best describes your organization’s status or performance. If none of the descriptions are applicable to your organization, place N/A under the comments section, along with other comments/suggestions, if any.

Capacity Areas	Capacity Levels			
	1 Low to basic	2 Moderate	3 Advanced	4 Outstanding
SYSTEMS AND STRUCTURE				
3.01 Organizational Structure Clarifies roles for organizational members, so that each member knows their responsibilities and to whom they report.	<input type="checkbox"/> Our organization does not have an organizational chart. Roles and responsibilities of staff (if any), members, and volunteers are not clearly defined.	<input type="checkbox"/> Our organization has an organizational chart which includes the chapters (if any) but is outdated. Roles and responsibilities of staff (if any), members, and volunteers are clearly defined. However, chapter roles and responsibilities are not well defined.	<input type="checkbox"/> Our organization has a clear and updated organizational chart, including chapters (if any). Roles and responsibilities of staff (if any), members, and volunteers are clearly defined but not regularly reviewed to reflect current realities in which the organization is operating.	<input type="checkbox"/> Our organization has a clear and updated organizational chart, including chapters (if any), which also reflects the current reality in which it is operating. Roles and responsibilities of the organization and its chapters complement each other, are formalized, and clearly defined.

Comments

Capacity Areas	Capacity Levels				Comments
	1 Low to basic	2 Moderate	3 Advanced	4 Outstanding	
SYSTEMS AND STRUCTURE					
3.02 Human Resource (HR) & Volunteer Management Systems Includes recruitment, management, and retention of staff, volunteers, and members.	<input type="checkbox"/> Our organization has no systems and processes in place for the recruitment, management, training, and retention of staff (if any), members, and volunteers. Recruitment of volunteers is done on an ad hoc basis.	<input type="checkbox"/> Our organization has a system and process in place for the recruitment, management, training, and retention of staff (if any), members, and volunteers. Our organization also has a basic system for administration of staff compensation, and benefits for members and volunteers.	<input type="checkbox"/> Our organization has internal expertise (or access to relevant external assistance) in HR planning and has an established system for administration of staff (if any) compensation and benefits for members. HR system and policies are informed by the principles of equity, diversity, and inclusion. Our organization also has an established volunteer management system in place.	<input type="checkbox"/> Our organization has an established system and process to recruit, develop, and retain staff and members. The system also includes a well-established volunteer management system. HR system and policies are informed by the principles of equity, diversity, and inclusion. Our organization has full capacity to manage HR functions and has an HR plan that is linked with the strategic plan and used to guide HR practice.	
3.03 Operational Planning and Decision Making	<input type="checkbox"/> Our organization rarely meets to discuss and decide on operational plans, activities, and key issues. Decision-making process is highly informal, and decisions are made on an ad hoc basis by one person and/or whoever is accessible.	<input type="checkbox"/> Our organization meets twice a year to discuss and decide on operational plans, activities, and key issues. Decision-making process is well established. Although generally followed, it sometimes breaks down and becomes informal. Decisions are informed and made by key leaders/managers and some selected members.	<input type="checkbox"/> Our organization holds meetings three to four times a year to discuss and decide on operational plans, activities, and key issues. Our organization has clear and formal systems for decision-making and decisions are appropriately implemented or followed most of the time. Decisions are informed and made by key leaders and representatives from various groups.	<input type="checkbox"/> Our organization holds regular monthly meetings to discuss and decide on operational plans, activities, and key issues. Our organization has clear and formal systems for decision-making and decisions are appropriately implemented and followed religiously. Decisions are informed and made by and shared with leaders and representatives from various groups, including underrepresented sectors/members.	

Capacity Areas	Capacity Levels				Comments
	1 Low to basic	2 Moderate	3 Advanced	4 Outstanding	
INTERNAL COMMUNICATIONS & INFORMATION MANAGEMENT					
3.04 (Internal) Communications Strategy/Plan Communications within the organization, and with members and/or volunteers.	<input type="checkbox"/> Our organization does not have any communications strategy or plan in place. Communications with staff, members, and volunteers are rare.	<input type="checkbox"/> Our organization does not have a communications strategy or plan in place. Key information regarding our organization and hemophilia updates are occasionally communicated with members and stakeholders.	<input type="checkbox"/> Our organization has a communications strategy and/or plan in place. Key information about our organization and relevant updates on hemophilia and other bleeding disorders are communicated to staff, members, and stakeholders in a generally consistent and coordinated manner.	<input type="checkbox"/> Our organization has a clear communications strategy and plan, which are regularly updated and are known to most staff, members, and stakeholders. Our organization has regular and tailored communication with members and stakeholders that always carry consistent messages.	
3.05 Information Materials	<input type="checkbox"/> Our organization does not have any published (electronic or printed) materials that introduce who we are and what we do.	<input type="checkbox"/> Our organization has some published materials that introduce who we are and what we do, but are not updated to reflect new programs and relevant information on hemophilia care and treatment.	<input type="checkbox"/> Our organization has a package of communications materials that are being used on a consistent basis. The information contained in the materials is up to date and reflects current programs, activities, and outcomes. Most materials are available as both electronic and print copies.	<input type="checkbox"/> Our organization has a well-designed, user-friendly, comprehensive package of communications materials that provide a good background on the organization, as well as the bleeding disorders care and treatment in the country. The materials appeal to a variety of stakeholders and adhere to clear "branding" standards. All relevant materials are produced in both electronic and print versions and are available both in English and local language. They are consistently disseminated and are kept up to date.	

Capacity Areas	Capacity Levels				Comments
	1 Low to basic	2 Moderate	3 Advanced	4 Outstanding	
INTERNAL COMMUNICATIONS & INFORMATION MANAGEMENT					
3.06 Website and Social Media	<input type="checkbox"/> <p>Our organization does not have a website, but has a Facebook page with minimal information and is only updated occasionally.</p> <p>Our organization has limited use of and access to other social media platforms.</p>	<input type="checkbox"/> <p>Our organization does not have a website, but has a Facebook page, which has general information about our organization and regular updates on hemophilia activities we organize.</p> <p>Our organization uses other social media platforms to promote and inform members and stakeholders about different activities.</p>	<input type="checkbox"/> <p>Our organization has a website with general information about the organization and useful information and resources for people with bleeding disorders (such as a list of HTC's, etc.). It is regularly updated with information on activities organized by our organization, as well as the WFH.</p> <p>Our organization considers social media as a useful tool and actively seeks opportunities to inform and engage not just the bleeding disorder community but also a wider network.</p> <p>Our organization also has guidelines for the use of social media in sharing information with staff and members.</p>	<input type="checkbox"/> <p>Our organization has a website with information about the organization and its chapters, useful information, and resources for people with bleeding disorders, including a list of HTC's with contact details, educational resources about hemophilia and other bleeding disorders, and regular updates on news and activities organized by the organization and the WFH.</p> <p>Our organization considers social media a useful tool and consistently and actively engages with the community through these channels.</p> <p>There is social media expertise and experience within our organization, guidelines are developed, and the initiatives are part of a broader communications strategy or plan.</p>	

Capacity Areas	Capacity Levels				Comments
	1 Low to basic	2 Moderate	3 Advanced	4 Outstanding	
ORGANIZATIONAL ASSETS AND INFRASTRUCTURE					
3.07 NMO Legal Status	<input type="checkbox"/> Our organization does not have any registration document.	<input type="checkbox"/> Our organization is not registered but is affiliated and operating under an officially registered entity.	<input type="checkbox"/> Our organization is registered with a local government agency to be able to operate legally but registration does not allow receipt of international funding.	<input type="checkbox"/> Our organization is registered with the appropriate government agency to be able to operate legally and receive international funding.	
3.08 Meeting/Office Space, Office Equipment, and Other Technical Resources (phone, computers, internet connectivity)	<input type="checkbox"/> Our organization does not have a designated office space or a permanent address but uses one of its member's (or Board member's) house as a meeting space. There is no allocated computer or phone for the organizational use. Members use personal computers and internet connectivity when necessary.	<input type="checkbox"/> Our organization does not have a permanent office but has been allowed to operate in an office space within the HTC. The organization's core group at the central level have access to computers and internet, but regional representatives or chapters have limited technical infrastructure.	<input type="checkbox"/> Our organization has office space, but it is shared with another organization. Adequate hardware and software infrastructures are accessible in the central office and other regions. Some limitations regarding accessibility may apply.	<input type="checkbox"/> Our organization has a rented space for meetings and other NMO activities. It has all necessary, fully networked computer hardware with up-to-date software applications. All the staff have individual computers and access to internet.	

COMPONENT 4: PEOPLE AND COMMUNITY

Description: Capacities of management team/staff, members, and volunteers.

Instruction: For each capacity area, please check the box that best describes your organization's status or performance. If none of the descriptions are applicable to your organization, place N/A under the comments section, along with other comments/suggestions, if any.

Capacity Levels

Capacity Areas	1 Low to basic	2 Moderate	3 Advanced	4 Outstanding
STAFF AND VOLUNTEERS				
4.01 NMO Staff and Management Team	<input type="checkbox"/> Our organization does not have full-time staff and relies on a few volunteers for daily operations and other activities. General operations of the NMO are managed by the Board.	<input type="checkbox"/> Our organization employs a part-time administrative staff who manages daily operations and coordination of various activities with the help of some volunteers. The administrative staff reports to and is supervised by the Board.	<input type="checkbox"/> Our organization employs a full-time manager and administrative staff to manage its daily operations and coordination of various projects/activities. The manager reports to and is supervised by the Board. Many volunteers actively engage and support the implementation of various projects and activities.	<input type="checkbox"/> Our organization employs a regular and full-time management team and administrative staff to support the work of volunteers, members, and chapters. The management team and staff are highly experienced in non-profit management and have distinctive capabilities from other fields. The management team develops strategies and recommendations to the Board in relation to the organization's growth and sustainability.

Comments

Capacity Areas	Capacity Levels				Comments
	1 Low to basic	2 Moderate	3 Advanced	4 Outstanding	
SYSTEMS AND STRUCTURE					
4.02 Volunteer Capacity	<input type="checkbox"/> Our organization has a limited number of active volunteers to support its functioning.	<input type="checkbox"/> Our organization has several skilled volunteers with diverse backgrounds. They are reliable and committed to the organization's success and offer support to the NMO whenever necessary.	<input type="checkbox"/> Our organization has very capable volunteers who bring the required skills to the organization. They are very involved and highly committed to the organization's success. They work in collaborative manner with most of the staff (if any).	<input type="checkbox"/> Our organization has extremely capable volunteers who bring complementary skills to the organization. They are very reliable and highly committed to the organization's success and contribute actively to achieving its set goals. They work in close collaboration with a wide range of staff.	
MEMBERSHIP AND COMMUNITY BUILDING					
4.03 Community-Building and Engagement	<input type="checkbox"/> Our organization rarely has community engagement activities where members get an opportunity to meet others and discuss common issues.	<input type="checkbox"/> Our organization holds several community engagement activities each year (at least two). Meetings are attended mostly by members who are based in the main city and virtual means of communication are provided for those living in remote areas.	<input type="checkbox"/> Our organization holds regular community engagement activities which are opportunities to listen to the community and respond to new perspectives or needs that are presented. Our organization evaluates its priorities and strategies to adapt to the changing realities of the community as need be.	<input type="checkbox"/> Our organization has a clear community engagement strategy. It reaches most of the country, through well-established programs in all the main cities and regions, in partnership with local representatives. Our organization consistently evaluates this program to adapt to the changing realities of the community.	

Capacity Areas	Capacity Levels				Comments
	1 Low to basic	2 Moderate	3 Advanced	4 Outstanding	
SYSTEMS AND STRUCTURE					
4.04 Chapter Development	<input type="checkbox"/> <p>Our organization does not have any chapters. However, we have identified one or two volunteers from at least one area outside of the country capital who can help in coordinating our activities.</p>	<input type="checkbox"/> <p>Our organization has a few chapters outside of the country capital which coordinate some activities in their respective localities. However, they have limited resources and a small group of members. They have contacts with HTC teams in the respective localities.</p>	<input type="checkbox"/> <p>Our organization has several established chapters outside of the country capital with some members. They coordinate activities in their localities and have good relationships with HTC teams in their areas. Basic roles and responsibilities and expectations between the organization and its chapters are understood by many of the members.</p>	<input type="checkbox"/> <p>Our organization has many established chapters outside of the country capital with a high number of volunteers and members. They coordinate activities in their localities in collaboration with HTCs. Our organization and its chapters have formal agreements which clearly outline their roles and responsibilities of, and mutual expectations. These are also known and understood by most of the members.</p>	

COMPONENT 5: FUNDING AND FINANCE

Description: Planning, organizing, controlling, monitoring, and growing financial resources necessary to achieve organizational goals and objectives.

Instruction: For each capacity area, please check the box that best describes your organization's status or performance. If none of the descriptions are applicable to your organization, place N/A under the comments section, along with other comments/suggestions, if any.

Capacity Levels

Capacity Areas	1 Low to basic	2 Moderate	3 Advanced	4 Outstanding
FUNDING				
5.01 Fund Development Fund development is the ongoing strategic positioning of an organization to sustain and grow its resources.	<input type="checkbox"/> Our organization can secure a minimum amount of funding from a few sources to cover its basic needs, but not enough to support strategic development. It has a project-based approach to fundraising activities.	<input type="checkbox"/> Our organization recognizes the need to develop systems for long-term financial planning and has a fund development strategy. The fund development strategy includes several activities. However, this is not well connected to a long-term strategic plan and budget projections. Fundraising activities are more opportunistic than strategic.	<input type="checkbox"/> Our organization can cover basic needs and attract enough diversified funding for various projects and programs according to its financial and fundraising policies. Some systems are in place for long-term financial planning. It has a fund development strategy which includes multiple activities and is mostly aligned with and connected to a long-term strategic plan and budget projections. The fund development strategy is more proactive than reactive.	<input type="checkbox"/> Our organization regularly receives diversified project and program fundings according to its fundraising and financial policies, and it can run long-term projects and cover other needs according to its strategic goals. Our organization also has a well-developed and documented system for long-term financial planning and fund development strategy. Costs and effectiveness of fund development strategies are regularly reviewed. The multi-pronged fund development strategy is proactive and integrated into budget projections and long-term strategic plan, but organization can react quickly to changes in the funding environment.

Comments

Capacity Areas	Capacity Levels				Comments
	1 Low to basic	2 Moderate	3 Advanced	4 Outstanding	
FUNDING					
5.02 Policies on Fund Generation Our organization does not have policies relating to receiving funds/ grants/support from pharmaceutical companies, other private funding, or donations. However, it has some form of guidelines that are used occasionally regarding relations with and/or receiving support from pharmaceutical companies as a safeguard measure.	<input type="checkbox"/> Our organization has some policies regarding funds/grants/support from private companies and institutions. The policies are not extensive, but they are clearly defined in terms of relations, engagement, and support from pharmaceutical companies as a safeguard measure.	<input type="checkbox"/> Our organization has clear rules and policies in place regarding fund generation from private companies, foundations, public institutions, and individual donors. External audits are done on an as-needed basis.	<input type="checkbox"/> Our organization has a monitoring process to ensure compliance with the rules and policies regarding fund generation. An external auditing process takes place regularly and the results are shared with our organization members.		
FINANCIAL MANAGEMENT					
5.03 Financial Systems and Processes Process of planning, recording, and reporting finances.	<input type="checkbox"/> Our organization has a bank account, and some ways of monitoring funds. Basic bookkeeping is done mostly by the treasurer or a (volunteer) finance officer.	<input type="checkbox"/> Our organization has a bank account dedicated to grants/funding, creates annual budgets, records financial transactions, and produces financial statements. An accountant mostly performs cash-flow management, bookkeeping, and other accounting duties.	<input type="checkbox"/> Our organization has bank accounts dedicated to each organization that provides grants/funding. It develops and reviews budget plans annually, monitors expenses and cash-flows quarterly, and produces and presents financial reports. An accountant performs the accounting duties and responsibilities.	<input type="checkbox"/> Our organization has different bank accounts dedicated to each organization that provides grants/funding, and has an annual budget created based on sound assessment and anchored on the organization's long-term financial plan. Accounting duties are performed by a certified public accountant (CPA), including preparation of annual audits, and other relevant tasks.	

Capacity Areas	Capacity Levels				Comments
	1 Low to basic	2 Moderate	3 Advanced	4 Outstanding	
FINANCIAL MANAGEMENT					
5.04 Internal Controls	<input type="checkbox"/> Our organization has some financial controls in place to ensure integrity in the bookkeeping process.	<input type="checkbox"/> Our organization has adequate financial controls in place to ensure integrity in the accounting processes.	<input type="checkbox"/> Our organization has financial systems and policies, and has internal controls in place that comply with generally accepted accounting procedures in the country. Audits are done on an as-needed basis.	<input type="checkbox"/> Our organization has a robust financial system and policies in place, including written comprehensive internal controls that comply with generally accepted accounting procedures in the country and adhere to accounting best practices. An external agency/ consultant conducts yearly audits.	

COMPONENT 6: COLLABORATION AND EXTERNAL RELATIONS

Description: Engagement, communication, and coordination with the WFH and other external organizations.

Instruction: For each capacity area, please check (✓) the box that best describes your organization's status or performance. If none of the descriptions are applicable to your organization, place N/A under the comments section, along with other comments/suggestions, if any.

Capacity Areas	Capacity Levels			
	1 Low to basic	2 Moderate	3 Advanced	4 Outstanding
ENGAGEMENT WITH WFH				
6.01 Participation in the WFH Programs and Activities	<input type="checkbox"/> Our organization participates in the WFH Annual Meeting of the General Assembly and WHD activities.	<input type="checkbox"/> Our organization participates in the WFH Annual Meeting of the General Assembly and WHD activities, as well as other selected WFH activities.	<input type="checkbox"/> Our organization actively participates in many WFH organized events and activities and occasionally seeks WFH collaboration for in-country programs and activities.	<input type="checkbox"/> Our organization actively participates in most WFH organized events and activities and regularly seeks WFH collaboration for in-country programs and activities.
6.02 Participation in WFH Data Collection Programs	<input type="checkbox"/> Our organization does not or rarely submits data to the Annual Global Survey (AGS).	<input type="checkbox"/> Our organization occasionally (one to two submissions during the past five years) provides data to WFH AGS; however, data are sometimes only partially complete.	<input type="checkbox"/> Our organization frequently (minimum three submissions during the past five years) provides data to the AGS on a yearly basis and helps WFH promote the use of Word Bleeding Disorder Registry (WBDR) and its app among HTCs and PWBDs.	<input type="checkbox"/> Our organization annually provides complete data to the AGS and actively helps WFH promote the use of WBDR and its app among HTCs and PWBDs.

Comments

Capacity Areas	Capacity Levels				Comments
	1 Low to basic	2 Moderate	3 Advanced	4 Outstanding	
ENGAGEMENT WITH WFH					
6.03 General Communication and Exchange with the WFH	<input type="checkbox"/> Our organization has limited communication with the WFH and vice versa. Communications with the WFH are only for specific matters and on an ad hoc basis.	<input type="checkbox"/> Our organization has occasional communication with the WFH Regional Manager. Our organization has a good understanding of the role of the WFH and its departments with whom we communicate for specific matters on an as-needed basis.	<input type="checkbox"/> Our organization has frequent communication with the RM and relevant staff. Our organization has a clear understanding of the role of the WFH and its different departments, and frequently reaches out to them for enquiries or requests.	<input type="checkbox"/> Our organization has very frequent and close communication with the RM and all other relevant staff at the WFH. Our organization collaborates with the WFH on joint programs and activities in the country, hence it is in close communication with various staff and/or volunteers.	
6.04 Reporting and Accountability	<input type="checkbox"/> Our organization rarely submits reports to the WFH and has no established processes in place to follow up on financial assistance received for our projects.	<input type="checkbox"/> Our organization submits reports irregularly to the WFH due to lack of human resources and systems in place. Reports provided are mostly submitted after the set timeframes.	<input type="checkbox"/> Our organization provides reports to the WFH as requested. However, some reports are not as detailed.	<input type="checkbox"/> Our organization provides thorough and timely reports to the WFH as requested. Our reports include key information on project outcomes, financial reconciliations, copies of receipts, and photos.	

Capacity Areas	Capacity Levels				Comments
	1 Low to basic	2 Moderate	3 Advanced	4 Outstanding	
EXTERNAL RELATIONS					
6.05 Ministry of Health or Other Health Authorities	<input type="checkbox"/> Our organization has no relationship with the Ministry of Health or other health authorities.	<input type="checkbox"/> Our organization has limited relationships with the Ministry of Health and other health authorities.	<input type="checkbox"/> Our organization has a good relationship with health authorities and sometimes participates in relevant government health committees and working groups.	<input type="checkbox"/> Our organization has strong and solid relationships with health authorities in the country. Representatives from our organization participate in relevant government health committees and working groups. Our organization has collaborative project(s) formally involving relevant government institutions.	
6.06 Health Care Providers (HCPs) - Local	<input type="checkbox"/> Our organization has limited communications with HCPs in the country.	<input type="checkbox"/> Our organization has some relationship and contacts with HCPs in the country and provides support when requested and available.	<input type="checkbox"/> Our organization has good relationships with HCPs in the country and collaborate on projects and activities together.	<input type="checkbox"/> Our organization has developed strong relationships with HCPs locally. HCPs support the work of our organization by providing advice and participating in committees and training. Additionally, our organization has developed relationships with international medical groups.	

Capacity Areas	Capacity Levels				Comments
	1 Low to basic	2 Moderate	3 Advanced	4 Outstanding	
EXTERNAL RELATIONS					
6.07 Other Patient Organizations	<input type="checkbox"/> Our organization is not aware of the existence of other patient groups in the field of hemophilia or other inherited bleeding disorders.	<input type="checkbox"/> Our organization is aware of the existence of other patient groups but has a minimum level of coordination or collaboration with them.	<input type="checkbox"/> Our organization is aware of the existence of other patient groups and regularly collaborates with them.	<input type="checkbox"/> Our organization collaborates with other patient groups on a frequent basis. The organizations closely coordinate and implement joint advocacy initiatives (and other projects, if relevant) to increase government support for bleeding disorders.	
6.08 Partnerships and Alliances with Other Organizations and Groups	<input type="checkbox"/> Our organization has no participation in any partnership or alliance.	<input type="checkbox"/> Our organization participates in partnerships or alliances with no clear impact on care or treatment.	<input type="checkbox"/> Our organization is actively engaged in partnerships and alliances with other associations focused on improving care in the country.	<input type="checkbox"/> Our organization actively participates in partnerships and alliances with other associations and groups (national or international) and takes part in their decision-making process.	
6.09 Local Media (TV, Radio, Press)	<input type="checkbox"/> Our organization has no relationship with local/national media.	<input type="checkbox"/> Our organization occasionally engages with local/national media outlets.	<input type="checkbox"/> Our organization has a good relationship with local/national media outlets and usually coordinates media releases with them.	<input type="checkbox"/> Our organization has a strong relationship with local media outlets. In addition to actively utilizing social media channels, all planned advocacy and/or awareness-raising campaigns of our organization are coordinated with the main local/national media outlets to increase our reach and impact.	

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